Miracles and Meltdowns

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What We Didn’t Know About Healthcare in America Until It Was Too Late

WALT CULBERTSON

The stories in this book reflect the author's recollection of events. Some names, locations, and identifying characteristics have been changed to protect the privacy of those depicted. Dialogue has been recreated from memory.

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Dedications

To Dr. Elizabeth, whom I so frequently think of and wish every physician could be—you were Deb's angel of mercy, compassion, and care. You enabled us to believe in the strength of hope and helped us find the will to endure.

To Jeanne, who gave me the greatest gift a mother could give and shared the most painful experience a mother can—every time I think of Deb, I am reminded of your courage, your strength, and your love.

To my sons, who grew up way too fast, encircled by the pain and reality of our own humanity—this prideful dad can see that you have clearly inherited your mother's courage, grit, and heart to thrive and survive.

To you, Baby, whom I do so miss and often see in my dreams—I am so grateful for the gifts your life brought. You taught me so much about love, and in losing you, I learned so much more about life.

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Foreword

Acknowledgments

So many times over the past fourteen years, I have picked up this manuscript only to put it back down. But finally completing what my late wife, Deb, asked of me in those last moments of her life, has proven more rewarding than almost anything else I have managed to accomplish during those years.

I am thankful to Mr. Michael Garrett, who was not only Stephen King's first editor and publisher, but my first editor as well. In late 2005, I sent Michael the birth of this book. Then part Deb's story, part Healthcare in America survival guide, he convinced me I was writing two works as Deb's story needed to be more than just four chapters in a self-help book.

I'm eternally grateful to Ms. Elizabeth Ridley. As my editor and counsel of words, she greatly assisted me through the last many months of my haunting challenge to finish and place Deb's story upon these pages. I am indebted to Liz for her editorial wisdom, sage insight, and ongoing support in helping me bring Deb's story to life. Investing much of her time and heart, Liz helped me bring through these words, not only justice for Deb, but for all those struggling with Healthcare in America.

It is because of these efforts and encouragement, as well as those this is dedicated to, and my other dear family, friends, and colleagues, that we have this legacy to pass on to others. Deb's cautionary tale, helping others learn, helping others to,

"Know what they do not know!"

Preface

American Healthcare Roulette

It is a sorry reality that within the age of great American might and everything we stand for as the grand nation, a book such as this must be penned, joining those that have come before it. As a healthcare expert with forty-three years of experience spanning all facets of the healthcare industry, I could never have foreseen, with all my years of experience, having to share how my own family fell victim.

I know that in finally finishing what I started fourteen years ago in the last year of my late wife, Deb's, life, and thus coming out of the closet, as it were, many of my healthcare colleagues may not understand nor be supportive. To all the hospitals and medical associations, physicians, health plans, and other wonderful colleagues who have supported my efforts and healthcare career over the decades, I can only share this. Over those years, as we have devoted much of ourselves in our own ways to efforts to improve Healthcare in America, things are only getting worse.

During the summer of 2001, then just eight months into my wife's battle with cancer, I wrote my first letter to a president. I concluded that outreach to President Bush with great sincerity as I pleaded for his headship. I did not blame, then or now, insurers, physicians, or hospitals individually. I blame the contorted, fragmented mess that has evolved to become Healthcare in America. Our disastrous non-system is not only failing those it is meant to serve, but it is also failing my dear colleagues.

The majority of Americans are blissfully unaware that we have such disjointed and siloed healthcare that has literally fallen down and is not getting back up for so many other Americans. They cannot fathom how easily they themselves could fall within the ranks of the unfortunate, as we did. You don't know what you don't know until you know it, and in healthcare, that is too late. When it is you or a loved one sitting across from a physician and it is your turn, often out of the blue with no warning, hearing the two most frightening words you will ever hear.

"I'm sorry!"

"It's cancer!"

If you are reading this, feeling blessed that you have insurance, don't. You are NOT immune. As I found out, even with two insurance cards in my wallet in the early days of my wife's battle, while working for two of the south's largest insurance companies. We still went broke and on the day my wife passed, I owed over $35,000 in medical bills. We never went without insurance a single day, even as we at one point were paying over $18,000 a year for our policy. I am an industry insider and thought I knew it all. But in writing this, I painfully acknowledge that no one does when it comes to Healthcare in America. All you can do is increase your knowledge and management of your health so you can increase your odds at the "American Healthcare Roulette" table.

The more serious your health challenge, the greater your odds of financial ruin and harmful care, with or without health insurance. Despite the hype and political proclamations, we do not have the best healthcare system in the world. Truly, in fact, we do not have a real healthcare system at all. We have Healthcare Roulette. We have healthcare that is built purely and simply on luck.

Whom do you happen to work for or not? Where do you happen to live? Is the medical provider or pharmacy you have been seeing or want to see in or out of the network for your health plan? Every year, that can change based on the whim or shopping of your employer. Even if your insurance doesn't change, your doctor may still drop out of being in network because of the insurer's fee schedule or the convoluted nightmare of contracts, requirements, and oversight. Private insurance companies or public payers such as Medicare do more than pay claims these days. They are looking over the shoulder of your physician and looking down at doctors, often telling medical providers how to practice medicine in order to get paid for services rendered. Overt and covert rationing of healthcare disguised as so-called quality programs.

We have the least equitable and most expensive per capita non-system of any nation on the planet. Some get unlimited healthcare and won't pay a dime. Others in desperate need of care can't obtain it or afford the price tag. Unquestionably, we have the best specialists, the best technology, and the best facilities that money can buy for the lucky Americans. For those not so fortunate, only when you are destitute and just about to go over the waterfall are you finally tossed a lifeline, long after less costly and more effective care could have been rendered, providing for a better outcome.

No one can argue that we have the best of the best. What we don't have, however, is the best for all Americans. It is expedient for the pundits, and those receiving campaign contributions or profiting from the institutionalized chaos, to discount reports that rank the United States far below other nations in delivering healthcare.

However, those who view our non-system with such complacency have never felt the anguish of sitting in the office of an oncologist and being confronted with the horror that your spouse's cancer is non-operable. Then, thirty minutes later, stark terror, when the only chance your loved one has is being denied—over money. Despite all, you are already paying to have health insurance. You learn the hard way that having health insurance does not guarantee access to care.

Our non-system does not provide rational access or financing. One wrong move, or diagnosis, can spell financial ruin and worse. We live in a nation where the poor and middle class end up spending more to receive generally worse care. This is the unsettling reality of Healthcare in America. A system designed for symptoms, not managing the disease.

As dissected in countless studies including the recent 2017 findings[1] by the Commonwealth Fund and Kaiser Family Foundation concerning eleven of the highest-income countries, we pay far more than any other nation. Yet we receive much less. We rank last in outcomes, equity, access, and administrative efficiency.

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[1] Bradley Sawyer and Daniel McDermott Kaiser Family Foundation (2017)
Mirror, Mirror 2017: International Comparison Reflects Flaws and Opportunities for Better U.S. Health Care - Accessed May 2019 through https://interactives.commonwealthfund.org/2017/july/mirror-mirror/

While some receive no care, others receive too much care. Through our evolution toward for-profit healthcare, we encourage some hospitals and physicians to perform unnecessary and sometimes costly medical procedures on patients who may not need them—while denying that same care to those who do. Our emergency rooms are clogged with patients who have no insurance or high deductibles because they can't be turned away, while others crowd alongside because they can't get in to see a doctor.

We charge some seven or eight hundred percent more than others, and the poor more than the rich for the same procedure delivered by the same medical provider. As I document through my wife's tragic journey, pricing disparities of tens of thousands of dollars are commonplace, and no barrier exists to stop the gouging of those under- or uninsured.

Even if you are lucky enough to obtain care, you stand a chance of going broke from a medical mistake, an admission to the hospital, or the prescriptions you take. Over the years, those familiar with my wife's excruciatingly inconsistent journey during her five-year battle have asked:

"If these things can happen to someone like you, who knows and works within the system, how can we ever hope to manage or survive?"

Sadly, in many cases, the reality is that they do not manage because they can't. Many powerful and moneyed interests control both the process and the propaganda. They will not go easily or quietly into the night. We lambast other nations' healthcare waiting lists. Yet we ignore what should be plainly visible. We don't have a healthcare list because we don't have a list. We have no idea how many are waiting or had to put off the care they need, sometimes indefinitely, often until too late.

Until all Americans are standing in the same checkout line in healthcare, the only individual ownership many will experience is ever-increasing odds of lifelong medical bills and inconsistent care or deadly outcomes. So now, your education begins, with the reality painted through the details of my late wife's journey of care, exposing everything right and wrong with our fragmented and costly "non-system."

Letter to Deb

Hey Baby

Time is such a brittle thing, Baby. Since I last gazed into your beautiful blue eyes, life has seemed to pass in a blur. Yet in so many other ways, time has stood still. I find myself shaken when I wake from a dream, only to realize I'm back in a reality that does not include you. The only way I can be with you now is in those dreams. Close my eyes and see your face. Feel the warmth of the summer and the beach where we spent our first months and that Fourth of July. The fireworks glaring in the sky, starting a journey that burst inside for so many years.

But some nights, with other dreams, seeing the pain and feeling that panic. Upon waking, it is not you, but the sterile smell of a hospital room that haunts me. Some nights I am fearful to close my eyes. Not knowing whether this will be a warm dream, or will I again relive the anguish and the overwhelming panic. It all hits me so hard each time I return to finish this promise I made to you.

I have struggled to find your courage, to confront that which you asked of me. To finish what I started writing in that last year of our life together. It is difficult to read the words scribed during that time. Much less, engrave more. To relive the moments day by day, through those memories, reports, and thoughts we managed to capture during your five-year battle against the disease and the system.

The notes from Dr. Elizabeth, the hospice team, and Nurse Nancy flash with horrific freshness. The insurance notice we received just a month before you would leave this place, denying your hospice care. Hearing that hospice was not "medically necessary," as judged by those who often bear the ultimate decision about Healthcare in America. Given all the healthcare challenges that befell you, that notice was the perfect, heartless symbol of all you had endured. One more stab upon many into your soul.

The last precious moments we would spend together, so carefully documented, yet so quickly lived. As I read our notes, I am transported back to that last Christmas we would gather as a family and share that space you so filled in our lives. Agonizingly recalling anew our last anniversary dinner three days later. How pained you were at all our sons had endured and been confronted with. One month later, I would stare into your beautiful blues eyes for the last time.

But you knew. Looking back, I can now see so clearly that you knew. I remain overcome by your courage and tenacity. I still marvel at how you ever made it out on that evening. The image of your face and those tears glistening through the candlelight are etched forever in my mind. You pushed back the pain and the wheelchair and pushed yourself to the edge. Things unraveled so quickly from that night on. It was a whirlwind of a month. It left me, our sons, our shepherd, your Cody-bear, and those who love you—without you.

You courageously confronted the harshest of human realities in the tortuous reincarnation of your painful childhood. You lost your father at such a young age and now had to see your own family struggle through that same experience. So many years later, it was the same disease and the same prognosis. All fought within a healthcare system that had seemingly changed little through all those decades. Only this time, it was your sons and those you loved trapped in your childhood nightmare.

But these days my chest swells with pride as I breathe in each day. I am blessed with the gifts you left me. Blessed with the opportunity to watch what we brought into this world grow. Our sons continue to excel in life, Baby. Like you, they have taken all the bad and molded it into strength. They are talented and remarkable young men. They have clearly inherited your spirit and determination. They are you in so many ways. I see that. I see you every time I look upon them.

But sadly, as I watch them grow, life is unfolding just as that grayhaired man in the corner of the restaurant forewarned all those years before. I remember how your motherly "don't mess with my cubs" tenacity reared its head as you watched his eyes fixed in our direction. You pointed him out because he was so intently staring at us and our one- and two-year-old Steven and Thomas.

I remember how your expression transitioned from fierce to concern as we watched his once-smiling eyes turn watery and grim. Well, Baby, all these years later, here I am. Living what he shared with us as he came over with tears in his eyes. He left our lives as quickly as he entered. In doing so, he left a foreshadowing that haunts me to this day.

"I just had to tell you what two handsome and well-behaved young men you have there. Embrace every day with them and each other," he said.

"One day you are going to be lonely and old and sitting in a restaurant watching a family across the room. Remembering when that was your family. Wondering where all those years went. Wishing you could go back and relive each one of them."

His eyes watered even more as he solemnly continued. "Say the things you wish you would have said. Do all the things you wish you would have done. Before you know it, they will be off to college and on their own. Before you know it, one of you will leave this world and one of you will be left alone."

Staring at our sons, he shared in parting, "I am so sorry to interrupt your dinner. But you look so beautiful together. I just had to share this with you. I wish someone would have told me all this a long time ago."

Sitting here today, I have so much remorse that I did not heed that simple, yet chaste wisdom and advice. Live each day as if it were the last. Say the things I wish I would have said. This remorse hits me hardest when I think about the day you tried to tell me that the battle was over.

It has gotten more difficult to reconcile the reasons I started writing this in the first place—given the sword the pages ultimately became. I will never forget that Thanksgiving Eve. When these pages were curled and stabbed through my heart. When you decided, after five years, the battle was over. The pain and mistrust that arose from your hospital experiences had collided with your anger and anguish about trying to pay for it.

You pointed to all these pages where we had methodically detailed your care miracles and medical meltdowns. We had documented the hard-learned truths about healthcare—that the hospital front door and all the walls around you can be fully covered by your health insurance. But that health insurance does NOT necessarily cover all the doctors and the staff working inside those walls taking care of you.

I remain disheartened that you felt compelled to think of divorce as the cure. You hurled that word so frequently at me during our last year together. In the middle of so many tragically difficult concerns and events unfolding, how could you even begin to dwell on such a remedy? Why in the world, or in all places, America, would a wife and mother have such thoughts?

As if you could divorce us from the legacy of the medical bills we had already accumulated and the many more you envisioned dominating your sons' futures. But, sorrowfully, I know financial concerns were not the only thoughts guiding your resolve.

I still clearly hear your trembling voice. Your pained whispering through the tears in the middle of that night. Lying by your side determined to never let go. Then the grief-stricken question that still rings in my ears:

"Hey, Baby. Why does healthcare hurt so bad?"

I failed you and our sons that night. I did not have the answers. Especially to those experiences that were ultimately piloting your steadfastness.

"The battle was over."

How could you not be frightened at the thought of returning to the hospital?

No one could have more artfully, nor directly, captured those sentiments than Dr. Elizabeth. We counted our blessings for her as she did the unheard-of that night and made a house call.

She embodies one of the raw emotional and human challenges of being a physician. One of the reasons I concluded many years before that becoming a doctor as I had planned was not my calling. As a physician, to know that your patient's time is near. Despite all you can do and all your best efforts and technology, your patient will succumb to mortal bounds. Often as I think of you, Baby, I think of her and that last time we would see her together.

Her report from that evening somberly concluded that which you made so clear.

"Pt was adamant last night about not going to the hospital because of prior experiences."

I still picture her sitting at your bedside, holding your hand and softy talking to you as she held a washcloth to your forehead. She could not shield with any doctor-patient veneer the pain in her eyes. Dr. Elizabeth not only rendered your care, she cared deeply for you, came to your rescue so many times. But there, late into the night on that Thanksgiving Eve, she knew, I think, there would be no salvation this time.

I came to dismiss as forethought that you would always defy the inevitable. Time and time again—as if to prove there was indeed a superwoman—you leapt mountains of pain. You whipped and throttled the many powerful forces that seemed to always be at odds against you.

But on that night, it was as if superwoman was being slammed against a block of kryptonite. You pointed to our carefully documented pages, and as we discussed your decision to end treatment, how could I not feel complicit with Lex Luthor?

Crying so hard at times we could barely understand each other, you pointed to these pages. Clutching them as you stared through me with your pain. You told me no more.

"I won't live through any more of this. I can't. I won't. I'm so tired, Baby. I just can't do this anymore. Is it OK, Baby? Can I just finally rest?"

It was then that the words of a friend, Dave, pierced through me like an electric shock, Baby. Just weeks before, Dave shared that his dad was sick for a long time and that he finally figured out what his dad was so pained with. How he struggled to ask it of those who loved him.

"Is it OK that I rest?"

Dave told me not to be surprised when that question came from you. I needed to be at peace with that. So, you could be too.

I could hear myself saying those words to you. But those were not the thoughts flowing through my head, Baby. So surreal is the word "hospice" when it is finally uttered. An option that was too painful to contemplate.

From the beginning of your healthcare journey, you were given no hope. You were given very little time. You seemed to have few options. But you turned an expected short battle into a long war, and all along the way, managing to stave off this most final act of care.

As I lay there that night holding you, Baby, I could still hear your breathing. Listening as the effects of Dr. Elizabeth's care took hold. For that short time, there was no pain. There were no tears. The room was not swirling so bad you could not move. There was just the whirling of the ceiling fan overhead. There was just the peace and solitude of a Thanksgiving Eve night.

But for me, the room was still swirling. As if I were the one with brain and lung cancer. As if I were the one on so many powerful medications. Replaying again the options Dr. Elizabeth gave you. Replaying again your words as you made the decision to not ever go back to the hospital where you suffered too many medical meltdowns.

Reaching around you and touching these cold pages. Realizing you still so tightly held them in your grasp and loathing every word I had written.

Not able to confront this with the same courage you were.

Not wanting to live that final chapter.

Not wanting to lose you.

But not wanting you to continue to live in hell.

Not wanting you to have to continue in such great pain.

I tried so hard to keep from waking you. It took so much to wrestle those pages from your hands. Not wanting to leave you or take my eyes off you. But I was resolute to destroy that which haunted me—these words.

Now I wonder. How long did you watch me sitting in your chair?

Watch as I tried to quietly rip apart each and every page. Front to back. I slowly and methodically tried to erase everything that had happened to you, Baby.

Your voice broke the silence. What you asked broke my heart.

To live that last chapter with you. To promise to document each and every moment as we had from the start of your battle, until the end. To glue these pages back together. To finish it! Others had to know. Doctors had to learn. So, united we would all ask:

"Why does healthcare have to hurt so bad?"

Well, Baby, it still hurts. I didn't even need all the medical tests and scans I've undergone since you left me to confirm it. I already knew from all that we lived together. A piece of my heart has died.

It lies there in my left ventricle. It is a very rare condition, I am told. They wonder when it happened. How I lost that piece of my heart. But it is no medical marvel. It is so clear to me. I lost that piece of my heart a little at a time.

"From the day that you started your battle, until the day we would part. A little was taken every day, taken from my heart."

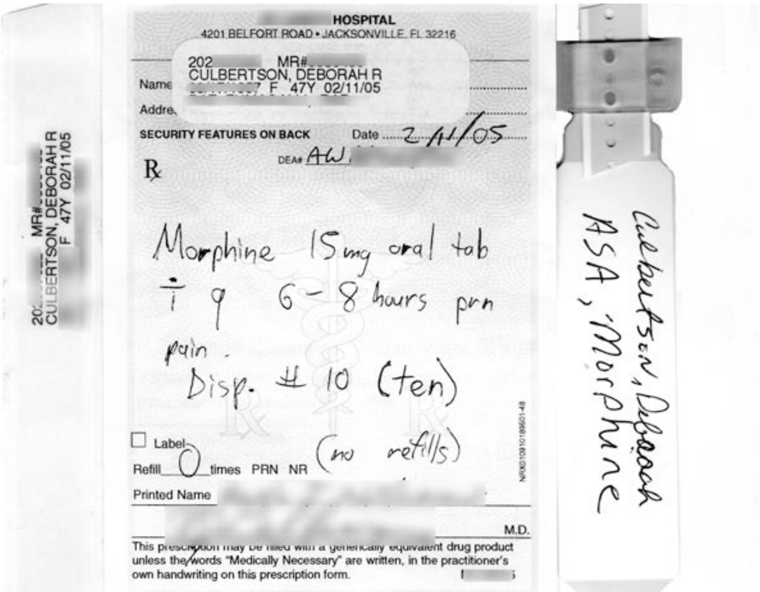
It has been so difficult to do this, Baby. To relive each of those days we spent together. I am so sorry that it has taken me so long to do what I promised.

But here it is. This is your story. Not only the story in which you fought the disease so heroically, but the story of your larger battle, the one from which you suffered the most, and to which you ultimately succumbed—Healthcare in America.

Our Crisis

Both Cancers Strike Again

Words can't express the waves of disbelief, heartbreak, and worry crashing within me, as I stared at my wife's orange allergy wristband, admission bracelet, and prescription that February of 2005. Hoping against hope the year of peace my forty-seven-year-old wife, Deb, had with lung cancer in remission, was not over. That the battle with cancer—the disease and our healthcare system—was not attacking anew. The orange bracelet clearly states Deb's allergy to morphine. Yet so does the prescription sitting next to it.



202[redacted] MR#[redacted]
CULBERTSON, DEBORAH R
F 47Y 02/11/05

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CULBERTSON, DEBORAH R
[redacted] F 47Y 02/11/05
Addre[redacted]

SECURITY FEATURES ON BACK Date 2/11/05

DEA# AW[redacted]

℞

Morphine 15mg oral tab
ī q 6-8 hours prn
pain.
Disp. # 10 (ten)

☐ Label
Refill 0 times PRN NR (no refills)

Printed Name [redacted]

[redacted] M.D.

This prescription may be filled with a generically equivalent drug product unless the words "Medically Necessary" are written, in the practitioner's own handwriting on this prescription form. [redacted]

NRX010910189601-48

Culbertson, Deborah
ASA, Morphine

Like all couples, we had certainly lived through peaks and valleys over our then-twenty-two years spent together, including nineteen as husband and wife. But in staring at Deb's prescription, I stared into the deepest of all valleys. I saw four years of a few miracles and many meltdowns flash before my eyes. I relived again how this healthcare war against cancer started on our oldest son Thomas's 12th birthday in 2000. It was a celebration that started as bowling with the birthday boy and his Irish-twin brother, Steven. But it concluded with Deb walking out of a medical clinic with an X-ray of her right shoulder.

Now, four years later (three years of battles and scars, then one year of Deb being pronounced cancer-free), we sat on the precipice of another battle opening up the war again. A new tumor had just been discovered in the original location in Deb's right lung. Everything went so very differently on that day in February compared to the biopsy four years before that foreshadowed the start of Deb's journey onto the battlefield. During that first biopsy, in early January 2001, the doctor more or less stumbled through the procedure.

But this time, the physician doing the procedure could see the CT image as he did the procedure. Previously, Deb could only wither and sob in the car as I rushed into the pharmacy on the way home. Today as we approached the pharmacy, there was no collapsed lung, no chest tube, and no severe pain. The nurses, the doctors—everyone—made certain the procedure went as smoothly as possible. Most importantly, the procedure was done as painlessly as possible. The doctors took great care to study the images beforehand. They carefully worked out the best approach and marked where to insert the probe. Unlike that first biopsy, in which the physician just winged it, this procedure was exact. It was careful. It was planned.

When the biopsy was over, several times we met with the medical team and discussed the weekend precautions. We talked about what they would provide for pain medication. Given Deb's allergy to morphine, this was always a common discussion and at times a challenging outcome to achieve.

"We'll make certain we make you comfortable," her doctors promised.

With those final details concluded and given prior experiences at this hospital, Deb and I were just relieved to be getting out in one piece. We were lost in so many feelings, worry, and disbelief. We never looked at the prescription buried among the paperwork as we left. We did not even remove her bright orange allergy wristband and admissions bracelet as we normally did. Deb usually wanted that evidence removed quickly.

As we had done so many times before, we stopped at the pharmacy that Deb had formed an all-too-"familiar" relationship with over the last four years. Looking around the intersection as we sat at the light waiting to turn, the area's growth was apparent. Once there stood only one standalone pharmacy competing against the grocery store pharmacy across the street. Now four pharmacies adorned this intersection. Just two miles down the road even closer to our home, three more sprang up at the intersection into our subdivision. If progress is measured by the number of pharmacies—then we live in paradise.

Deb wanted to go inside to pick up a few sale items rather than drop off the script. But within minutes, however, I looked up and saw Deb headed my way with that look I had seen many times before.

"They didn't have it," Deb grumbled. "But they checked down the road and they got it there. So, let's just go and drop the damn thing off and get home and figure out dinner for the boys!"

Fortunately, there was no line at the drive-thru and we were able to immediately pull up to the drop-off kiosk. Deb handed me the script and I slid it into the tube and off it went. We were greeted with the traditional pharmacy hello crackling in the speaker, "Your last name and date of birth, please!"

After several minutes passed, we instinctively became uneasy at the wait. Finally, the pharmacist came back with another crack of the microphone and very matter-of-factly pronounced, "We can only do a partial fill of the order. We do not have enough quantity on hand."

At this Deb's blue eyes glazed red and she leaned across me. Raising her voice into the speaker while trying to look over at the window and the pharmacist, she snapped, "I was just at the other store and they called you guys and you said you had it!"

"Yes, ma'am, we do. We just don't have enough to completely fill your order right now," the pharmacist cracked back through the speaker.

Deb was really digging into the armrest of the seat and fuming. "So how many do you have and when can I get the rest?"

I listened in disbelief as the second pharmacy in a row could not fill the prescription. Not because I could not believe it could not happen, but because it was occurring on a late Friday afternoon. This is one of the feared axioms of healthcare. Often very little gets accomplished over a weekend, except for runs to the emergency room and urgent care centers.

Sure enough—after some silence, there was finally another crackle.

"We can give you five now. Our next delivery will be on Monday."

At this point, I knew we could not give up—not on a Friday. The only thing I could quickly think of was asking the pharmacist to try another of their stores that was about five miles away in the other direction. I was agitated but relieved when the pharmacist shot back after another little wait, "Yes, sir, they have it at the other store and are holding enough to fill the script."

As we waited for the script to be returned through the kiosk, it was clear Deb's patience had dissolved. "I can't believe they can't fill the whole damn thing here."

The effects of the day starting to show on her face, Deb hoarsely added, "Since we gotta go back in the other direction anyway, let's go get the boys and eat out."

Taking the script out of the cylinder and closing the lid, my first thought was "Booyah! I don't have to hustle dinner tonight!" As I started to hand the script back to Deb, I finally took a closer inspection of the little white piece of paper that was causing so much fuss.

"What the hell is so hard to get?"

But my next thought was sheer bewilderment. I stared at the prescription in disbelief as my eyes danced between the script and the bright orange band still adorning Deb's wrist as she reached out to take the script from my hand. Our year of healthcare peace was shattered in an instant. It was a foretelling of what was to be.

Morphine! The script was written for morphine. It was the same exact word written on the allergy band around her wrist.

How could the facility that had been treating her for so many years write that order? To say nothing of the fact they did it while Deb was wearing that allergy bracelet. They knew better than anyone of Deb's medical history and its myriad complications stemming from her severe allergy to morphine. While Deb seemed to tolerate certain pain meds in the same class as morphine, she developed something called anaphylaxis when given straight morphine sulfate.

On this day, two times Deb handed the prescription to a pharmacist. If you are assuming pharmacists always know your allergies—think again! No one asked Deb if she knew what she was getting or if she had any known allergies.

Two times all she heard was, "Sorry, we don't have any." Not, "I'm sorry but our records indicate you're allergic to this!"

We learned long ago, at the end of the day, you have to stay on top of your own care. You have to be your doctor's helper and become part of your care team. We also learned how important it was to have another set of eyes and ears. The role of a patient's advocate is a critical bridge and balance.

It was bad enough for the new pharmacies that sprang up overnight to be uninformed. But it was hard to understand the first pharmacy we stopped at down the road. The pharmacy we used with great frequency for almost four years. Pharmacists increasingly play a critical role in our care plan. Yet most often, all that connects them with our doctors is a single, scribbled, cryptic note on an oversize sticky.

With millions of dollars in technology and who-knows-how-many hundreds of years of combined knowledge from one of the best and most skilled medical teams in our nation, in the end, it all came down to a single, frightening little piece of paper. But I blew it more than anyone or anything else had.

I knew better.

I let my guard down.

I let Deb down.

I let our sons down.

I never looked at the script until that moment. I took it for granted, based on the discussions we had at the hospital, with the doctors, to say nothing of her documented history, they would never give Deb morphine.

At the realization of what had just occurred, I was crushed. I also knew this part of the drill all too well. There was no way the pharmacy could do anything to change the medication. At now five o'clock on a Friday, we stood no chance of quickly getting anyone on the phone that could change Deb's prescription. As I started to launch into what was now happening with the voice on the other end of the speaker, Deb stared at me in disbelief, and it was clear she was now beyond it all.

"Just get my ass home! I'll deal with it. I'll deal with the pain over the weekend on my own. We always have to!"

As I tried to get Deb to consider the consequences as we drove away, she was now adamant that she would just get through the weekend and the pain. She understood well the herculean task of trying to get another prescription after being discharged from the hospital outpatient facility. Trying to get someone from the now-on-duty team to look at her records and provide another script would not be a quick fix. In all likelihood, a Monday afternoon fix.

It was a very long weekend. We did not talk about the events of Friday much. Fortunately, because of the great care and skill of the medical team (other than writing that script), Deb appeared not to be in so much discomfort. Thankfully, Deb had a moderately painless weekend.

But the silence between us spoke louder than any words we could have shared. We were each lost in another place into the beginning of the week, trying to put on a normal face and routine for our sons. Silently fretting and trying to make it through each day until we knew. Deb attempted not to show it—but I knew it. It was written all over her beautiful, yet pained, face.

After more than two decades of staring into those beautiful blues, I knew her so well. I was twenty-seven when we met during the spring of 1983, the early days of computerized medical practices. I had written my first networked practice management system and was at a medical conference with my dad, Walt Sr., who was helping me get the business started. As I gazed across the crowded exhibit hall floor as the conference was about to open, a twenty-five-year-old beauty strolled through the exhibit entrance as if she owned the place.

A tall, beautiful, long-legged blonde, Deb quickly gained the attention of everyone around her, including, obviously, me. She was dressed in a low-cut white blouse with tassels across the front matched with a tight black skirt with lacy black stockings and black heels. She was very much aware all eyes were upon her. When I heard my dad share aloud, “Lord have mercy,” I knew I was not the only one whose eye that tall blonde had caught.

For the next two and a half days, while we were busy trying to sell the interested doctors or make small talk with the others that came up and down our aisle, no booth was busier than that copy & supply business Deb was working for. The tall beauty held centerstage. Even those doctors and their staff who had initially tried to walk past her, could not. Deb drew them in. She was amazing to watch in action. It became quickly clear this was not just a pretty face. Calling Deb a booth draw would be an extreme understatement. As Dad said on or about the second day, “Jesus, that girl can hustle!”

After the conference, as Dad and I were tearing down and most of the other vendors around us were as well, I looked up and saw the blonde beauty walking straight and deliberately our way. She held a piece of paper in her hand and I guess I kind of looked away from her, completing what I was sure must be the sad picture of the proverbial shy computer nerd. My dad, however, had no problem stepping up to the plate in greeting her.

“Hi, I’m Deb,” she said as she reached for Dad’s hand and they shook hands as she handed Dad a piece of paper she held in her other hand. She clearly was now looking in my direction.

“I thought after a long conference, you fellas could use a good laugh,” she said, still looking at me.

As Dad took the paper, he introduced himself. “Hi, I’m Walt and this is my son, Walt,” Dad said, laughing as he read the off-color joke that Deb’s stepdad, Ken, had given her. I would later learn all about Ken’s down and sometimes dirty sense of humor as the family entertainer and jokester. I honestly can’t remember what joke was typed on that piece of paper. What I recall is my heart almost stopped when she took the paper from my dad and slowly walked over and stood very closely next to me. She was flashing the most beautiful set of blue eyes I had ever seen. Deb's gorgeous smile was adorned with what seemed to be another trademark, ruby-red lips.

She made a joke about me being part of the "Walt and Walt show!" Then she reached for my hand, shaking it. I melted on the spot.

"Well, Walt Janay Rorer," Deb said, drawing out the J and the R with a huge smile. "You have been standing over here for three days staring at me and you never once came over. So, what—you thought you were just going to let me walk out of your life without ever even saying a word to me? So now that you made me come to you, what's the next move?"

I didn't know what to say. But I would later learn from my dad and his ribbing that I turned beet red. I can't remember what I stammered out, but again Deb took charge.

"So, I am off Friday, and I think that would be a good day for you to take me to lunch. So you got any plans, Walt JR?"

Stammering, all I could think of was, "I guess I do now," as she wrote down her number and the name of the place for us to meet at, "High noon!"

But as Friday approached, I had a major challenge brewing. One of the doctors we had met at the conference was insistent that we meet him and his office manager on Friday during their lunch break. I did not dare turn him down or push for another time as he was the head of a large practice and very active in the local county medical association, as he bragged at the conference. His support would have been a lucky break and opportunity to get started in that community.

It was with great trepidation that I called Deb. I knew that canceling would certainly speak more loudly of my priorities of the day than any words I could wrap around my call to her. I figured someone as beautiful and in-demand as Deb would just blow me off, telling me to "have a nice life," and that would be that. "See ya!"

But to my surprise, I instead heard a very long pause on the other end of the phone. "So you are telling me some doctor is more important than me?"

I tried to explain as best as any computer nerd and wannabe entrepreneur could why on earth someone like me would be trying to postpone a date with someone like her, for of all things a doctor. But once again, as Deb was capable of proving she could most certainly do, she took charge.

"Well, Walt. So here is what I think we are going to do for you putting me off. You meeting any docs on Saturday night?"

Before I could even get a word out, Deb continued. "So now, instead of lunch, you are going to take me to dinner on Saturday night and I have the perfect place!"

As soon as I heard "Lobster Pot," I knew my wallet was in deep trouble. All that my dad could do when I told him what went down was to shake his head and laugh his butt off with the same observations at the conference.

"Man, that girl can hustle!" and "Son, I think you're in deep!"

Sitting across from Deb would indeed prove to be one pricy meal that evening, but it was forever priceless in a thousand other ways. No price tag could be put on being there with her that evening. Able to sit across the table and get lost in those amazing blue eyes, exchanging chunks of our life stories was such a special feeling. Most of all, I was the one she chose to be with—all so very priceless indeed.

Deb's personality sparkled as much as her external beauty and playful sexiness. I was so quickly drawn in. She had great spunkiness, strength, and directness about her with a Southside of Chicago-girl toughness, where she grew up. She was complex, displaying not just stoutness, but also warmth in a unique way. Her great sense of humor was on full display that evening. She put me, with all my initial nervousness, at ease. Dad was so right. "I was in way over my head."

What was nervous infatuation at first blush at the conference was now unquestionably proverbial love at first sight. We closed the place down, talking and talking for hours until we had to take the hint from the staff. We sat up all night on the beach talking until our first kiss. When the sun came up, we walked to a small beach diner to finish one of the most amazing evenings of my life with coffee on the beach.

Now here we were, twenty-one years later, plus two children, exactly four years after we began a far different and nightmarish journey that had started with two words no one wants to hear coming from your doctor, especially an oncologist.

"I'm sorry" quickly followed by "it's cancer!"

Once again, we found ourselves hoping against hope that when the results of the new biopsy came in, we would not be hearing those same two words again. Unless you have been in the position of being at the mercy of our healthcare non-system and it failed you, it is difficult to comprehend how often it happens. As patients, we have little choice but to hope those we entrust with our lives are treating us with the utmost care and skill, and for reasons other than greed. Based on my wife's courageous journey, I now know this is not always the case. There is so much needless pain and suffering and mental as well as physical anguish. Miracles do happen, but they can be excruciatingly painful.

While the following is but my wife's journey, along the way we have met many traveling the same path, wandering through the same maze of complexity and inconsistency. Without question, we were fortunate to have been touched by angels, doctors and nurses who made the unbearable at least endurable, risking much to be advocates for their patients.

There were wonderful and gifted physicians, such as my wife's oncologist, Dr. Elizabeth. Every day this remarkable doctor uses not only her skills as a physician, but also her humanity and heart, to instill determination and hope for life. There was the surgeon, Dr. Sandy, who, though unscheduled and burdened by so many other responsibilities and patients, assumed care in the middle of a crisis, preventing a sure course toward total collapse.

There was a wonderful, simple promise from Dr. Todd, a pain management physician who assured my wife, "I will never let you live or die in pain," and then reached out in the middle of the night from far away to keep that promise.

But I am sorry to say that we also suffered less laudable traveling companions. Deb's journey was also touched by those in control of her passage who fell short of human decency, let alone professionalism and compassion. It is sadly obvious to some physicians that the Hippocratic Oath was something that was said and promised—but not to be lived up to.

But in order to truly appreciate these medical encounters of the best and worst kind and how we arrived at that ominous day of February 11, 2004, let's step back in time and relive what led up to that day of consequence.

The Journey Begins

Our journey began in late 2000 on our oldest son Thomas's 12th birthday. Deb and I always tried to make this a special day, casting aside the challenges of having a child whose special day just happens to fall close to the Christmas holidays. We had traveled down to Deb's parents, Ken and Jeanne, who after so many years of love and closeness were as well fully my parents. It was slated to be a fun morning spent at the bowling alley as part of the merriment, but Deb had to stop bowling abruptly within the first few frames.

"My shoulder is really hurting today," she explained. "You guys finish my game."

In the weeks prior, Deb had been complaining of some mild pain and discomfort in her right shoulder. But the tough Chicago girl chalked it up to her annual activity of making special faux-stained-glass items. Deb had a special talent and ability to create beautiful stained-glass visuals using gallery glass paint to simulate a stained-glass effect on glass or hard plastic surfaces. She even simulated the leading around the geometric shapes of colors. You really needed to study the piece closely to determine that it was not real stained glass or lead. Her gift creations on cake plates, bowls, jars, and flat surfaces to adorn a wall or window, were treasured by family and friends lucky enough to receive them.

"Too much stained glass for Christmas this year," and with that Deb had simply written off her shoulder discomfort.

My biggest worry as I sat in the outpatient urgent care facility near our mom Jeanne's house was winding down my "dudes" from the bowling, soda, and burgers they had for lunch and downshifting the birthday fun to sit quietly in a waiting room. Because the place was not crowded, I had hoped this would be a quick in and out. But almost two hours later, I joined my two sons in impatiently waiting for their mom to appear from the back. We were all anxious to continue the birthday celebration at Grandma's house. I was now concerned something worse was emerging in the back than overwork from Deb's artwork.

When Deb finally did appear, she had a large X-ray jacket in her hands. Looking at her face as she walked toward us, I knew something was not right even before she could softly murmur, "We'll talk later."

But Thomas and Steven were not having any of that! They could read their mom's face almost as well as I could.

"What did they say, Mom? Are you going to be OK? Are we still going to the park, Mom?"

They continued to pepper Deb with questions until she finally returned to the present from wherever in her thoughts she just was.

"Yes, dudes, everything is fine. Yes, we are going to the park."

But once at the park and alone while our "dudes" were all over the monkey bars, it was my turn to start peppering Deb with my own questions as I looked deep into those blue eyes.

"What did they say, Baby? Why did they give you a chest and shoulder X-ray? What's going on?"

Her blue eyes started to turn watery and, uncharacteristic of Deb, her voice turned soft then started to quiver as she said again, "We'll talk later, Baby. Everything will be OK. But don't say a word to Ma."

When we got back to Deb's parents' place, she turned and looked back at the boys in the backseat. With that look and voice that we all knew very well meant business, Deb sternly cautioned the boys against saying anything to anyone about being at the clinic earlier! As we crossed the threshold of her mom, Jeanne, and stepdad, Ken's door, Deb magically transformed. No one would have ever thought she had a care in the world. Her frown miraculously turned upside down. No one, not even her mom, at that point, knew what had transpired during the day or anything about the day's events as Thomas and Steven got lost in the birthday fun.

Later that evening, as Deb and I retreated to the bedroom for the night, I nervously confronted Deb. My shock turned to fear as Deb finally told me that the pain in her right shoulder was not caused by spending too much time on her stained-glass artwork. No, it was something far different.

"They saw some kind of mass in my right shoulder that extended from the top of my lung. They don't know what it is, but they made an appointment for me to have a follow-up at a cancer doctor next week."

Eight long days later, on December 28, 2000, our fifteenth wedding anniversary, I sat with Deb in another waiting room. The sign on the door this time read in part Cancer Institute. I will never forget the brave look on my wife's face at the words finally uttered coldly and flatly by the oncologist.

"While we need to get a biopsy to make certain, it is probably cancer."

It seemed more like a year rather than the weeks that it took to get the biopsy procedure scheduled. Yet, when the time finally came, we had no idea that what would take place would portend the frightening confusion, pain, and horror yet to come. Things started bad and got worse. Her doctor had promised Deb the option of being put to sleep for the procedure, but the stark truth we heard at the nurses' station as we checked in that day was clear.

"They never put anyone out for this; your doctor knows that!"

Still, the nurse assured my wife that she would be made comfortable, as the procedure was expected to take just a short time.

As I paced up and down the hallway, all the desk nurse could say was that the doctor was with her and she should be out shortly. Almost two hours later, they wheeled a different Deb from the back. Instead of my tough-as-nails Chicago girl, they brought out a vulnerable woman with tears streaming down her face. As Deb slowly got into our minivan we had dubbed our tribe-mobile, she tried not to hit or move the chest tube still embedded pitifully in her side. Instead of being made comfortable, I heard an account of a biopsy procedure that was far worse than having a baby.

Instead of both local and intravenous pain meds, all Deb received was a series of painful local anesthetics delivered around her armpit. Instead of planning, pinpoint precision, and upfront discussion, little was said as she was pushed into the CT tube. The shots did little to dull the pain of having to hold her arm for the entire procedure over her shoulder where the cancer was located. Using the side of her body as a tray table, the physician leaned into the CT tube and stuck the biopsy needle near her armpit.

A technician who was, in turn, watching a scope of where the biopsy probe was going, verbally guided the physician. In and out and all around the doctor went with the large needle, while the technician kept telling him, “Move laterally! Move laterally!”

The doctor, however, could not seem to follow the instructions and kept maneuvering the wrong way.

As time passed, and the doctor could not get to the correct location, he became visibly angry. His disposition did not improve when Deb’s lung collapsed, and he had to take the time to insert a chest tube. His anger intensified as my wife kept telling him that she was in extreme pain. It was all Deb could do to keep her arm up, especially during the unplanned chest tube insertion and the repeated episodes of lung collapse.

During the first hour of an outpatient procedure in what amounted to torture, the doctor flatly stated that he had “no more drugs for her.”

Each time he had to stop, insert the tube, and wait for the lung to inflate again, his anger grew noticeably. He kept looking at the clock, obviously thinking of his already-overbooked schedule of patients for that day. Nevertheless, he doggedly kept collapsing her lung.

Finally, the doctor got the needle into the correct place. At that point, he threw whatever instrument he was using down and barked to those left behind to “deal with it.” Sitting there exhausted with a chest tube in her, Deb listened in disbelieving horror as they told her the lung could collapse again and the tube would have to remain in place for twenty-four hours.

That night, watching every breath Deb took, was one of the longest nights of my life. Or so I thought at the time. I could never have foreseen the journey ahead, given all my years spent in healthcare and thinking that I knew healthcare. The next day, after hearing of the previous day's events, Jeanne, who while on paper was adorned with the title of my "mother-in-law," was in life and love my mother, was determined no one would do that to her daughter.

This time our mom went with us to have the chest tube removed. She refused to take no for an answer at the front desk and she demanded to go back with her daughter. When the doctor walked into the room and saw them both there, his mood did not improve from the day before. He asked no questions about how the chest tube did during the night or whether Deb had any problems. But he did inquire why Jeanne was in the room as he literally screamed at his staff and next barked at Deb to "move over" as he plopped himself down next to her.

Before Jeanne could even finish her protest, or explain why she was there, the doctor barked at Deb to, "hold your breath."

Then, with no further warning, he reached down and viciously ripped the tube out of Deb's side. It was obvious, given the way the nurses comforted Deb after he departed, they were all too familiar with this doctor's "bedside manner." They promised to complain and told her to report the incident to her referring doctor, but you could see their dread, and Deb was certain there would be no court of appeal.

It was another week before Deb, Jeanne, and I would nervously sit in silence awaiting the verdict that had caused sleepless anticipatory nights. The diagnosis was rendered as bluntly as this battle leading into a long war had started.

"I'm sorry" were the first words from the oncologist as Deb tightly gripped my arm as the news continued—"Cancer!"

The oncologist gave us no details and no answers. Was it operable? "We don't know."

What is the prognosis? "We don't know."

For now, a consult with a surgeon, then immediate chemo and radiation to get the tumors under control, then "we'll see." When Deb and Jeanne tried to discuss the biopsy incident, all we heard from the oncologist was that the biopsy was over.

"You won't have to worry about going back there again," was all that her doctor would say of the biopsy procedure.

We walked out and got in the car in stunned silence, and I could not even bring myself to put the tribe-mobile into reverse. We sat for the longest while in excruciating silence. Mom was the first to speak.

"We will make it through this as a family."

Jeanne comforted us with her love and knowledge, and there was little doubt, looking into her familiar blue eyes, as Deb bore a strikingly strong, beautiful resemblance to her mom. She would absolutely be there and do everything and anything she needed to or could. Mom was sadly experienced in ways Deb and I were not yet, and I don't know how we would've persevered without her being there with her great love, support, and with a Dutch determination that quickly ignited Deb's own Dutch vigor.

Having never seen a cancer battle before and with only a cursory knowledge of such things, twelve-year-old Thomas and eleven-year-old Steven took the news as could be expected, focusing their questions circularly around one.

"You'll be OK, right, Mom?"

Deb gave them, and for that matter me, all the reassurance we needed to hear in that heartrending moment.

"You guys already know there's nothing tougher than me," she promised. "We will do what we have to do, the doctors will do what they have to, and yes, I'll be OK. I ain't going anywhere!"

Deb confronted her next heartful task just as courageously. She started with her twenty-six-year-old son, Ray, from her first marriage, then onto her sisters Vicky and Laurie. Deb doughtily shared the news with the same fighting spirit she had broadcast to our sons and me. Unsurprisingly, each was devastated at the mention of that word—"*Cancer!*" Especially the girls, given this same disease and location had befallen their father when he was just thirty-two. Equally shattered were Deb's aunts, Shirl and Arlene, and her uncles, John, Jim, and Tom.

As I knew well from many years together, Deb's surface could appear beautifully calm and level, but the seas beneath might be churning wildly. As each night unfolded unto the next during the days that followed, I lay in a bed of Deb's private world she shared with no other. She was falling into a nightmare reemerged decades after it had first started. She was twelve and her sister Sandy thirteen, Vicky nine, and Laurie just seven when her father Ray's battle started. It was the same disease in the same location. It had a devastating impact on her family and their world.

Unquestionably, Deb had concerns for herself, but her prominent focus was our sons. Deb could not shake the surrealism of Thomas and Steven being exactly the same ages as she had been. More than anything during those insufferable nights, the tidal wave of overwhelming fear and devastation over our sons was the turbulence striking her hardest. But each morning she again arose as the morning before. Seemingly untrammeled and sailing once again on placid seas as she got the boys off to school and proceeded onward through her day.

The following week we met with the surgeon. After looking at the X-rays, the CT scans, and the notes from the oncologist, he said Deb's great pain was caused by the size and complexity of the tumors in the right lung that had spread into a sensitive location of the right shoulder. Because of the many critical nerves and blood vessels in that area, until the tumors could be reduced, she was "not yet" operable.

However, the surgeon also expressed concern about an area in her left lung and the lymph nodes in the neck and ordered more tests and scans. Bone—liver—brain—breasts—abdomen and a magical test called a Positron Emission Tomography or PET scan. We were to quickly learn how expensive it was. Radioactive sugar water is injected and then filmed as it travels through the body. Everywhere cancer is present shows up as a dark black spot on the film. Although we would much later tragically learn, it doesn't work everywhere in your body as we were just told!

In this case, not only did the spots in my wife's right lung "light up," but also a ring around something in her left lung and a small streak going up her neck. While the oncologist agreed that cancer had metastasized to the lymph nodes, she discounted the spot in the left lung. We had no precognition at that time what dire consequences this misdiagnosis would cause.

As frightening as the looming chemo and radiation were, two more hurdles needed to be jumped before treatment could begin.

First was getting the pain under control. Since the biopsy procedure, Deb could barely move her arm, or lie on her back, and was now only able to sleep sitting up. She would also have to undergo a surgical procedure to insert a device called a "port-a-cath," which would be used to deliver the chemo. It was decided that, in order to accomplish both, Deb would be admitted to the local hospital where the oncologist had privileges.

During Deb's stay at the hospital, they failed to get her pain under control. Deb's severe allergy to morphine was one nemesis that she would constantly battle. But we were feeling fortunate at that point because our insurance authorized a referral to the pain management specialist. As we witnessed throughout Deb's journey, obtaining good pain relief was among the most disheartening and challenging aspects of her care.

Getting the vascular access device or "port-a-cath" put in went smoothly. The inserting surgeon called it "a truly magical device." It sits under the skin and is spliced into the subclavian vein, which flows directly into the main blood supply of the heart and would be used for chemo treatments as well as drawing blood or delivering other intravenous fluids. As the physician looked at her tiny veins, he promised proudly, "no more pain."

However, that would not be the case. From the first procedure at her office, the oncologist refused to allow the port to be utilized for anything except chemo delivery. She strongly cautioned my wife to never let any other doctor or facility access the port, including the lab. While we were confused by the promise versus the reality, at least the chemotherapy had started.

Polaroid Therapy

So did a weekly routine that both mother and daughter would describe as their full-time jobs. I do not know what we would have done without Jeanne's help. Every day of every week there was somewhere Deb needed to be. She had to visit the oncologist, radiologist, lab or diagnostics facility, pain management, and several times the hospital, E/R, and surgeon. But the days of her weekly radiation were the most difficult of all. Even though many radiologists were within our health plan's network and much closer, the oncologist insisted on a particular radiologist who was forty miles north. It took several hours each way through a heavily traveled and congested route to reach the radiologist's office. But it was more than the distance that troubled my wife about this radiologist.

The radiologist had great difficulty communicating his thoughts, at least in English. His answers to questions always came in the form of totally unrelated euphemisms and analogies. When all else failed, he would resort to pulling out a stack of Polaroid pictures. Early on, Deb told him that she was having great difficulty swallowing. She also asked if there was something he could give her for the radiation burns on her neck and chest. Deb told him of another chemo patient who advised using a cream available only by prescription.

At this query, the radiologist pulled out his stack of photos, revealing patients scarred with severe radiation burns. He explained that these were people with <u>real</u> burns. Her skin was fine, he told Deb, just continue to use the recommended over-the-counter lotion and continue to drink hot tea for her throat.

He used those pictures again the last day he would treat Deb. Normally scheduled for six hours, that day her oncologist increased the flow of chemo to run in only four hours to remedy a scheduling conflict with the radiologist. During the two-hour drive after chemo, Deb kept telling her mother she did not think she could go through with the radiation treatment that day and her throat felt like it was almost closed.

As Deb tried to tell the radiologist she did not want to undergo radiation, he pulled out his stack of pictures he kept in his white jacket. He showed Deb pictures of patients who were severely deformed with large tumors. He told Deb that if she did not want to be one of those pictures, she could not give up and must push herself to get through the treatment. Deb decided she had to try to make it through the treatment on her chest and neck.

The radiation machine sits in the middle of a lead-lined room. Once the procedure starts, the door is closed and sealed. The staff (and others, as it turned out) would keep an eye on the patients through several TV monitors at the nurses' station. As the table started to lift into the air to allow the machine to move into place underneath her, Deb could not swallow and started to choke. She tried to get the nurses' attention, but the table was too high at that point for her to get off, and Deb was afraid to sit up once the radiation started. The table on which she lay was many feet in the air. No one was looking at the monitor to see her. No one saw her hands, arms, and legs flailing about as she gasped for air.

We are so fortunate that Jeanne made it her habit to position herself in the waiting room where she could view one of the monitors—a HIPAA privacy violation for which I will be forever grateful. Deb's mom happened to glance up from her reading to look at the monitor. Horrified at what she saw, Jeanne yelled at the nurses that her daughter was in distress.

"Don't you see what is happening with my daughter? Open that damn door immediately!" Jeanne screamed.

The nurse immediately hit the emergency shutoff, at which point Deb tried to sit up. As the nurse waited for the room to clear and the door seal to release, she tried to get Deb to lie down. She repeatedly told her through the intercom to lie down until she could lower the table. Unable to breathe, coughing and gasping for air, Deb, of course, could not comply.

Within an hour of arriving home and looking at her daughter's worsening condition, Jeanne called the oncologist. The oncologist said to take Deb immediately to the hospital E/R and instruct them to check her into a room and tell the staff that her doctor would meet her there. Doctor's orders seemed to have no effect, however, as they were still told on arrival to simply take a seat in the waiting room. The waiting room seemed to be populated with mostly flu victims.

Her mother asked whether that was wise, given how sick her daughter was and all the warnings about Deb's chemo-weakened immune system. They were informed the hospital was so filled to capacity, if they had come by ambulance, they would have been diverted to another facility. Never mind that this was THE one where Deb's doctor had privileges. Several hours passed before Deb was finally called into the back to meet her doctor. After ordering immediate blood work and an IV, the oncologist left to check on the admitting paperwork.

After another considerable amount of time, the oncologist walked back into the room and stood at the foot of the E/R table, watching the scene in front of her. The doctor said little as my wife sobbed and tears streamed down her face as the nurse tried time after time to force the needle into one of her tiny and rolling veins. At this point, they were watching a second nurse desperately trying to get the IV started.

The oncologist, who was also a hematologist, never made any effort to do it herself. She just stood and watched the nurses, who were clearly feeling every jab along with Deb. Finally, after watching the nurses work their way up and down both of her hands, wrists, and arms, the oncologist coldly ordered, "Try her ankles."

At that time, we were ignorant. But what we later learned about how Deb's port-a-cath should have been accessed, was not merely incompetence, but cruelty. Especially as Deb's oncologist not only just stood by and allowed the jabbing up and down Deb to occur, but also directed it.

The final insult came after the oncologist ordered Deb to be admitted and left. The hospital prepared Deb's room for the night—a stretcher in the hallway with a half dozen other patients. All appeared to be in various stages of the flu. Considering the experiences of that day, and given concerns about catching the flu on top of everything else, Deb, with her mother by her side, demanded, "You either take me out of this hallway or release me so I can recover at home in my own bed away from all these sick people!!"

After an initial protest from the staff, Deb signed the forms and Mom was allowed to collect Deb and leave. Over the next days, as she started to recover, Deb and Jeanne decided to tell the oncologist they wanted to finish treatment with another radiologist. But at the oncologist's insistence, Deb made one more attempt to talk with the radiologist. While Deb wanted to discuss the events of the week before and his plans for the final treatments, all she got was more analogies. After again not getting any straight answers, Deb decided enough was enough.

She refused treatment that day and demanded her records at the front desk. But the radiologist refused to turn over any of her records without consultation from the oncologist. Later that week, with her mother by her side, they forced the oncologist to allow Deb to go to another radiologist that was within our insurance network.

It would turn out to be one of the best decisions Deb could have made. The new radiologist was ten minutes down the road from the oncologist's office. Also from another country, he spoke perfect English and took great care to make certain he answered all Deb's questions. His office was modern and clean.

Unlike the older machine used by the first radiologist, this one was precise and much more accurate. It burned the skin far less. The radiation did not overflow up her neck to cause throat complications. Even before Deb could ask for the cream her chemo friend had told her about, this doctor wrote Deb a script for something far better than the over-the-counter stuff she had been trying. He even gave her a sample to take home and begin using. No pictures of the scarred, burned, or tumors were waved in her face. The experiences were like night and day.

In Sickness or in Wealth

The day finally came when we would get the results of the needlessly painful tests and procedures. Early summer of 2001, now approaching six months since the nightmare started, I sat with Deb, Jeanne, and the oncologist once more. She was again blunt and she was direct.

"After consultation with the surgeon, I have determined that your cancer is non-operable and that you should continue with chemotherapy."

As we were trying to digest this latest news, we were asked to wait in another room for more information. Would Deb be offered other options for chemo? Was there something else that could be done, we wondered? But that conversation would not unfold as we had expected. It veered off and made a turn down a much different path.

Thirty agonizing minutes after being told chemo was Deb's only option, the nurse, who had established a caring relationship with Deb, was now asked to perform in a much different capacity—billing clerk. She walked in with her eyes swelling, and it was not with Deb's medical records. Instead, she laid Deb's ledger on the table. With obvious reluctance, she relayed orders from the oncologist.

"The doctor has authorized me to tell you that before we can continue treatment, you must bring your account current. Your insurance companies have denied payment on many of the claims."

I sat stunned, staring at the statement just printed and seeing that I would have to write a check for $7,698.56 in charges outlined in front of me, or her doctor was going to stop treatment. Thirty short minutes after learning chemo was the only chance my wife had, I was now hearing it was going to be stopped—<u>over money</u>.

"God almighty American dollars."

PATIENT NAME: DEBORAH CULBERTSON

❷

STATEMENT DATE	PAY THIS AMOUNT	ACCT. #
06/20/01	$7698.56	[redacted]

PAGE NO. 1

SHOW AMOUNT PAID HERE $

[redacted]

☐ Please check box if above address is incorrect or insurance information has changed, and indicate change(s) on reverse side

STATEMENT

PLEASE DETACH AND RETURN TOP PORTION WITH YOUR PAYMENT

0-B-729

Date	Doctor	Description	Code	Charge	Paid	Balance Due
✓ 01/08/01	[redacted]	OBSERVATION LEVEL 2	99235	450.00		329.20
03/30/01	❶	Paymnt-GE #4 CK#2929			-44.80	
03/30/01		Adjust-GE ADJ#4 CK#2			-76.00	
✓ 01/10/01	[redacted]	ESTAB PAT OV EXTENDE	99214	100.00		80.00
01/24/01		Paymnt-PT PMT #3 CAS			-15.00	
03/31/01		Paymnt-PHOE #2-3 DED			0.00	
03/31/01		Adjust-PHOE ADJ#2-3			-5.00	
✓ 01/19/01	[redacted]	ESTAB PAT OV EXTENDE	99214	100.00		80.00
01/24/01		Paymnt-PT PMT #2 CAS			-15.00	
03/31/01		Paymnt-PHOE #2-3 DED			0.00	
03/31/01		Adjust-PHOE ADJ#2-3			-5.00	
✓ 01/31/01	[redacted]	ESTAB PAT OV EXTENDE	99214	100.00		15.00
03/30/01		Paymnt-GE #21 CK#294			-85.00	
✓ 02/16/01	[redacted]	HOSP ADMIT LEVEL 3	99223	400.00		76.50
04/24/01		Paymnt-GE #54-55 CK#			-178.50	
04/24/01		Adjust-GE ADJ#54-55			-145.00	
✓ 02/17/01	[redacted]	HOSP VISIT LEVEL 3	99233	225.00		46.50
04/24/01		Paymnt-GE #54-55 CK#			-108.50	
04/24/01		Adjust-GE ADJ#54-55			-70.00	
✓ 02/27/01	[redacted]	ESTAB PAT OV BRIEF	99211	30.00		30.00
06/18/01		Paymnt-PHO #22-34 RE			0.00	
✓ 02/27/01	[redacted]	CHEMO ADMIN INTRAVEN	96410	110.00		110.00
06/18/01		Paymnt-PHO #22-34 RE			0.00	
✓ 02/27/01	❸ [redacted]	CHEMO ADMIN INTRAVEN	96412	285.00		285.00
06/18/01		Paymnt-PHO #22-34 RE			0.00	
✓ 02/27/01	[redacted]	CARBOPLATIN 50 MG	J9045	720.00		720.00
06/18/01		Paymnt-PHO #22-34 RE			0.00	
✓ 02/27/01	[redacted]	PACLITAXEL, 30 MG	J9265	1500.00		1500.00
06/18/01		Paymnt-PHO #22-34 RE			0.00	

PLEASE PROVIDE ADDT'L INSURANCE INFO OR REMIT PYMT
PLEASE PUT THE ACCOUNT NUMBER ON YOUR CHECK WHEN SENDING IN PATIENT BALANCE

Statement Date	Account #
06/20/01	[redacted]

Make Checks Payable To:
[redacted]
FOR BILLING QUESTIONS
CALL MON - THR 10-2PM
[redacted]

Patient Amount Due	►►►►►►	7698.56
❹ Insurance Pending	►►►►►►	48028.00
DUE BY PATIENT	►►►►►►	$7698.56

***Learning Opportunity**: ❶ Compare the dates-of-service and insurance processed dates. Processing took between two and four months. ❷ First statement procedure performed was <u>six months</u> prior to the statement date. ❸ It took <u>four months</u> to process and deny all of the 02/27/01 services—Deb's first chemo session. ❹ Even as the $7.6K stopped Deb's chemo, there was still $48K of insurance outstanding.*

Underlying the shock was confusion. I asked the nurse how this could happen when we not only had insurance, we had several months of overlap from two insurance plans. After Deb was diagnosed, we made the decision to move even closer to Deb's family and mother, Jeanne. I gave up my healthcare consulting practice and self-employment to join a large healthcare technology firm that specialized, ironically, in insurance company claims systems, specifically to have those benefits. I was trying to avoid just the position we now seemed to find ourselves in. We immediately started to follow up and determine why the unpaid services were denied.

[redacted]

EXPLANATION OF BENEFITS

ISSUE DATE	PAGE [redacted]
July 6, 2001 ❶	001 OF 018

Sequence Number: 000000000
Subscriber's Name: WALTER L. CULBERTSON JR
Identification Number: [redacted]
Group Number: [redacted]
Group Name: [redacted]

WALTER L. CULBERTSON JR
[redacted]

Product: [redacted]

Patient's Name: DEBORAH CULBERTSON
Service Date: 01/04/01 - 04/05/01 ❶
Total Billed: $4,340.00

Provider of Services: [redacted]
Place of Service: Office
Patient Acct. Number: [redacted]

Paid Amount: $0.00
It is your responsibility to pay: $4,340.00 ❷

THANK YOU FOR USING A NETWORK PARTICIPATING PROVIDER.

SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	❷ AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
	TOTAL THIS CLAIM	4,340.00	4,340.00	0.00	0.00	0.00	0.00

DETAIL MESSAGE:
❸ 01 - Additional information has been requested regarding this claim. Once received, this claim will be reopened and benefits will be determined.

THIS IS NOT A BILL

Learning Opportunity: ❶ *Compare the dates-of-service and the claim processed dates on page one of our eighteen-page EOB from 7/6/01. The insurance processing time was <u>six months</u>.* ❷ *Note that "Amount Not Allowed = Patient Balance."* ❸ *The reason the processing was being held up and the services performed ultimately denied, was because the insurance company was requesting additional information.*

Leveraging my deep-domain knowledge of the industry, and working closely with the health plans, we were furious when I finally got to the bottom of things. I quickly discovered the reasons for rejecting the charges appeared to be the result of errors and omissions by the provider herself and/or her billing service! Also, repeated requests for more information and clinical documentation from the insurance company were always lost between the doctor's billing service who filed the claim and the oncologist who created it.

The worst insult came during the middle of the process. Even though both the insurance company and the doctor's office verified they were in network, over the months we learned the hard way that was not the case with the first insurance company. We were being billed for thirty percent of what was called "reasonable and customary (RC)" charges. In almost every instance, however, the doctor's charges were much higher than what the insurance deemed reasonable. So, we not only paid our thirty percent but were balance-billed for the portion that was in excess of what the insurance would not pay.

Although my own professional career spans the spectrum of the healthcare industry, I was overwhelmed by the daunting challenges and time it took to address the bills alone. I was determined early on that I would never again face the humiliation of having life-saving care denied to my wife. It would seem that each of us would have our battle with the system. Throughout our participation in the continual and recurring dialog with medical providers, their billing services, and insurance companies, all of them merely pointed the finger at the other. Meanwhile, valid services were denied payment.

[redacted] **Credit, Inc.**

CLAIM DEPT [redacted] Post Office Box [redacted]

ACA
INTERNATIONAL
The Association of Credit and Collection Professionals
Member

October 17, 2005 ❶

090 00 SH1 22807 [redacted]
Deborah R Culbertson
[redacted]

CREDITOR [redacted] **Hospital**

Attention: Patient Account Services
Toll Free: (800) 660-4279
Alt. Telephone: (904) 953-6470

ACCOUNT **NUMBER:** [redacted]
AMOUNT DUE: $1,495.29

Service Date: **02-28-05** ❶

Dear Deborah R Culbertson:

PLEASE SEE IMPORTANT NOTICE ON BACK

This letter will serve to inform you that your overdue balance with [redacted] **Hospital has been referred to Computer Credit, Inc., a debt collector (referred to in this letter as CCI). The hospital insists on payment. CCI is not aware of any reason for your nonpayment, therefore we expect you to pay the balance due. The law prohibits CCI from collecting any amount greater than the obligation stated above.**

***Learning Opportunity**: ❶ Compare the date of collection to date of service. Barely <u>seven months</u> had passed. We had not yet received our final appeal determination. We ultimately prevailed and the bill greatly reduced paid in-network.*

In many instances over the years, collection agencies have threatened even before the final determination of liability was made! In most cases, you won't even find out what the services you are receiving today will cost you, until many weeks or months later when the surprise comes in the mail. In this instance and many others, we have a "you don't know what you don't know until you know it" healthcare system, and then it's too late. Try to recover your money from the collection agency you paid at the "list price" after the claim was adjudicated at the prices the insurance company ultimately paid.

So many Americans are happy with their insurance plans not because they're getting the healthcare they want, but because many are only looking at one thing, what they have to shell out every month. Never realizing why their salary seems to be stuck in the past along with decent raises. Never realizing until it's too late there was a reason why, compared to other insurance plans, theirs is so cheap. Never knowing until it's too late, what happens when you have skimpy benefits and narrow networks of physicians who will take their insurance.

Considering that we are more fortunate than most to possess an understanding of the treatment and diagnosis codes, as well as how the system works, I cannot begin to contemplate how less fortunate Americans are managing the enormity and complexity of such a healthcare process.

As I reviewed Deb's explanation of payment and benefits (EOB), it became clear that it is nearly impossible to completely reconcile the statements from the doctors and other providers of care and insurance companies. The provider's statement had many individual procedures on the same statement, while the insurance company seemed to bundle many treatments together. Many times, we received statements from organizations we never heard of who evidently had some part in the complex treatment process. The most difficult part of all is that few produced anything that actually said what it was. Most were cryptic descriptions or my favorite, simply and coldly stating, "Medical Services."

Imagine staring at a bill and every line is a different amount, some dramatically so, yet all you see next to each is healthcare service. In the case of Deb's first oncologist, I saw clearly that, even though my wife was receiving the same basic treatment through the same process by the same staff each week for her chemotherapy sessions, the services and charges could vary dramatically each week.

In my attempts to resolve these discrepancies, I uncovered duplicate line items for procedures costing into the many thousands of dollars. Band-Aids described as hundred-dollar dressings. "Miscellaneous" supplies billed at over four hundred dollars per visit on top of another detailed and billed list of supplies and bills for encounters that never occurred. I remain to this day appalled.

[redacted]

EXPLANATION OF BENEFITS

ISSUE DATE	PAGE
July 6, 2001 ❶	009 OF 018

Sequence Number: 000000000
Subscriber's Name: WALTER L. CULBERTSON JR
Identification Number: [redacted]
Group Number:
Group Name:

Product: [redacted]

WALTER L. CULBERTSON JR
[redacted]

Patient's Name: DEBORAH CULBERTSON
Service Date: 03/27/01
Total Billed: $2,113.00 ❷

Provider of Services: [redacted]
Place of Service: Office
Patient Acct. Number: [redacted]

Paid Amount: $977.96
To: [redacted] ❷
It is not your responsibility to pay: $1,135.04

THANK YOU FOR USING A NETWORK PARTICIPATING PROVIDER.

SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
03/27/01	Medical Services ❺	1,500.00		1,006.89/01			493.11*
03/27/01	Medical Visit	120.00					120.00
03/27/01	Medical Visit	250.00		25.00/01			225.00
03/27/01	Medical Visit	100.00		58.00/01			42.00
03/27/01	Medical Visit	4.00		3.00/01			1.00
03/27/01	Medical Visit ❹	15.00		13.65/01			1.35
03/27/01	Medical Services	30.00		12.00/01			18.00
03/27/01	Medical Visit	54.00		16.50/01			37.50
03/27/01	Medical Visit	40.00					40.00
	TOTAL THIS CLAIM	2,113.00	0.00	1,135.04 ❷	0.00	0.00 ❸	977.96

DETAIL MESSAGE:

01 - This is the amount in excess of the allowed expense for a participating provider. The member, therefore, is not responsible for this amount.
* This Explanation of Benefits shows how we processed the claims for services received

***Learning Opportunity**: ❶ Page nine of the eighteen-page EOB from 7/6/01. It took four months to submit and process this claim. ❷ Health Plan negotiated reasonable & customary (RC) rate was a 53.7% discount. ❸ Just half-way through the year we had already met our full deductible for my new insurance company. ❹ Only one of two medical service descriptions is used to describe every single line item. ❺ Take particular note that all procedures were performed on 03/27/01and that the first procedure is for "Medical Services" billed for $1,500.00.*

We even determined that the oncologist had been overpaid by thousands of dollars Even as she had stopped treatment because she was not paid for some charges, we saw others where she had actually filed claims against both of my insurance companies for the same procedures, including chemo treatments, on the same dates during my insurance overlap period. Many of the charges were double-billed. We alerted the doctor and her billing service about all of this, and the insurance companies seemed unconcerned.

[redacted]

Employee Original

Date 05/10/01
Page 1 of 2
C010511A

❶ THIS IS YOUR
EXPLANATION OF BENEFITS

PARTICIPANT: WALTER CULBERTSON
SSN: [redacted]
PATIENT: DEBORAH
GROUP: [redacted]
LOCATION: [redacted]
DESCRIPTION: [redacted] COBRA
CLAIM NO: 24697[redacted]

WALTER CULBERTSON
[redacted]

Date	Total Charge	Exclusions			Copay	Deductible Amount	Covered Expenses	Pay %	Amount Payable
		Ineligible	CD	Discount					
[redacted]			CHEMOTHERAPY						
03/27/01 Procedure Code: 96410	110.00	Patient Number: [redacted]					110.00	70.00	77.00
03/27/01 Procedure Code: 96412	285.00	190.00 Patient Number: [redacted]	UC				95.00	70.00	66.50
❹ 03/27/01 Procedure Code: J9045	720.00	Patient Number: [redacted]	JC	260.90			459.10	70.00	321.37
03/27/01 Procedure Code: J9265	1,500.00 ❺	Patient Number: [redacted]	JC	924.72 ❸			575.28	❷ 70.00	402.70
			INJECTION						
03/27/01 Procedure Code: J1260	120.00	Patient Number: [redacted]					120.00	70.00	84.00
03/27/01 Procedure Code: J1642	250.00	Patient Number: [redacted]	JC	171.25			78.75	70.00	55.13
Totals	2,985.00	190.00		1,356.87			1,438.13		1,006.70
							Base Deductible Amount		
							Other Carrier Adj.		
							Total Paid		1,006.70

PATIENT IS RESPONSIBLE FOR ALL DEDUCTIBLES, CO-PAYMENTS AND CERTAIN INELIGIBLE AMOUNTS.

Description Codes as used above/Misc. Comments

[redacted] payer number is [redacted]
UC CHARGE EXCEEDS THE USUAL AND CUSTOMARY ALLOWANCE
JC CHARGE EXCEEDS THE USUAL AND CUSTOMARY ALLOWANCE

Payable To	Checks Issued	Amount	Date
[redacted]	[redacted]	1,006.70	05/10/01

***Learning Opportunity**: ❶ This claim is from our initial insurance company. ❷ Despite what we had been told, the oncologist was out of network. We paid a 30% copay. ❸ We also paid the difference of the reasonable & customary (RC) discount. ❹ Charges from many days of service were double-billed and <u>paid by both of my payers.</u> These charges from 03/27/01 are just one example. ❺ They are the same dates and charges appearing on previous 7/6/01 statement from other insurer.*

"It all gets cleaned out in the wash," the customer service representative from one of the insurance companies would say.

Later in Deb's care, as we were reflecting on not just the bad care, but the many billing errors that we uncovered and all the exorbitant costs that are dramatically reduced if we are fortunate enough to have them approved as "in network," we wondered about the true cost of all this. Over the years, as Deb and other patients compared notes during hours-long treatment sessions, many confided to her that they were fortunate enough to have their bills paid by someone else. Many long ago gave up trying to question anything, both because of the complexity and dubious nature of the paper trail, and previous efforts often not well received.

Even with insurance, however, those who are <u>not</u> fortunate enough to have a doctor or specialist available within their networks and must utilize the out-of-network coinsurance were going bankrupt every day, and that was before the so-called bankruptcy reforms. Many because they have no capability of having the charges reduced to a reasonable amount before having to pay their coinsurance penalty of what appears to be the inflated charge, in addition to the excess amount above what the insurance would pay. A reduction for the insurance company often translates into a deadly increase for you.

Imagine walking into your grocery store and there are no prices on the shelves for any of the products anywhere in the store. You have no idea what you are about to pay until you get to the cash register at checkout, or so you think. As you stand in line, you notice that the person on your left happens to be purchasing the same thing you are, as well as the person to your right. It seems that bottles of orange juice are in big demand and flying off the shelf that day. You listen as the cashier asks the person on your left if they had their grocery insurance card. They present their card and as it is scanned, you hear, "Yep, we are part of your grocery network, so that will be fifty cents today for your grocery co-pay."

While you wait in line, the person on your right steps up to their cashier. They immediately hand over their grocery insurance card and the cashier dutifully scans it in and fires back, "OK, it looks like you will owe a seventy-five-cent co-pay on that bottle of juice, and because you have not met your grocery deductible yet, you also have to pay the price difference of what your grocery insurance company negotiated. So that will be another two twenty-five on top of your co-pay, so we estimate that you will owe us three dollars today. But the good news is all that should go to your grocery store deductible."

But the unhappy customer sees no good news in what he just heard as he must pay $3.00 out of pocket on top of the price already being paid to have that card in the first place. As he questions the math, all the cashier can offer is this:

"Your grocery insurance company will send you a final settlement statement, and if we over- or underestimated what you needed to pay for that juice today, your insurance company will determine that and your bill will be adjusted accordingly," she says with a smile.

Then it is your turn to step up to the register. You hand over your card and very quickly hear, "I'm so sorry, sir, but we do not accept your grocery insurance."

You protest, "How can this be, you accepted my card here last month, so why not now?"

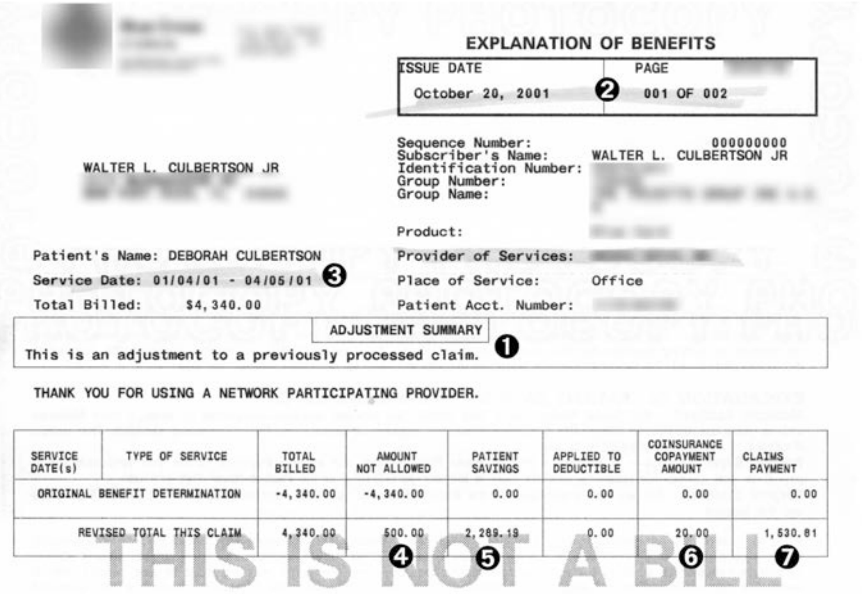
You receive a seemingly simple explanation. "Well, sir, I guess somewhere along the way, we stopped working with your grocery insurance."

"But this is the only grocery store within thirty-five miles that accepted my grocery insurance," you insist, yielding loads of sympathy, but little else the cashier can do. What you hear next is even more maddening as the cashier looks up the "cash" price of a bottle of orange juice in their system.

"Looks like that will be six dollars and ninety-seven cents." When you ask, "Why?" the cashier can offer no meaningful logic or reason you must pay 249 percent more. Seems everyone in the store pays greatly different prices for the same item in the exact same store delivered in the same exact way.

If the grocery store really worked that way, Americans would be up in arms and never stand for it. Yet that is exactly how the one thing in our lives we have no control over functions when we need healthcare. Unlike the mythical grocery store, week by week we lived through real-life examples of three-thousand-dollar charges that are reduced to eight hundred if paid in network. Six-hundred-dollar services reduced to less than one hundred dollars when your magical insurance card works the way it is supposed to.

As I scanned the claims over the months Deb had been treated, some of which even the doctor had just received given the claims paperwork time lag, none of the claims singularly stood out. But cumulatively, the claims piled up to seven thousand dollars. When the insurance company finally received all the information needed and paid the bills, those amounted to around twenty-two hundred paid in network. From me, an individual she thought underinsured, the oncologist was demanding seven thousand six hundred. From the insurance company, the bill was a little more than two.



[redacted]

EXPLANATION OF BENEFITS

ISSUE DATE	PAGE [redacted]
October 20, 2001 ❷	001 OF 002

Sequence Number: 000000000
Subscriber's Name: WALTER L. CULBERTSON JR
Identification Number: [redacted]
Group Number: [redacted]
Group Name: [redacted]

WALTER L. CULBERTSON JR
[redacted]

Product: [redacted]

Patient's Name: DEBORAH CULBERTSON
Service Date: 01/04/01 - 04/05/01 ❸
Total Billed: $4,340.00

Provider of Services: [redacted]
Place of Service: Office
Patient Acct. Number: [redacted]

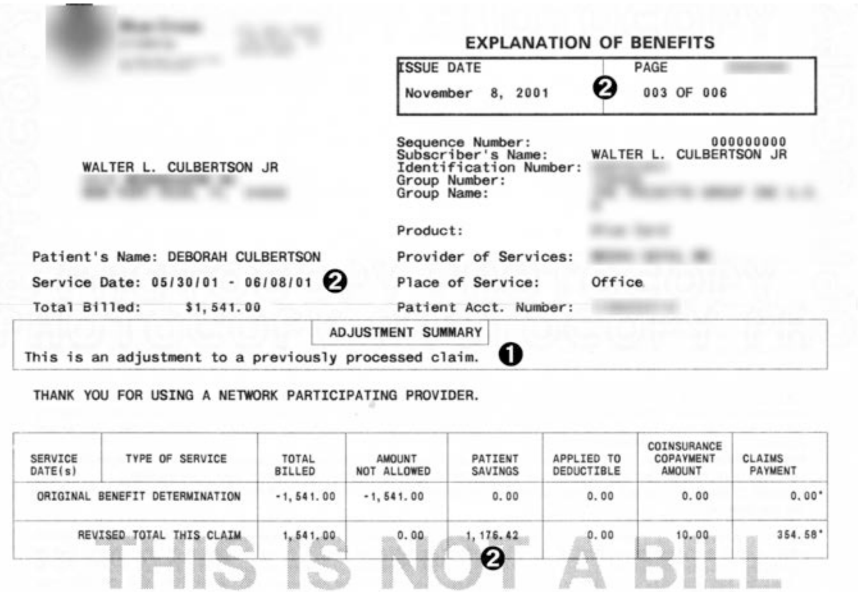
ADJUSTMENT SUMMARY
This is an adjustment to a previously processed claim. ❶

THANK YOU FOR USING A NETWORK PARTICIPATING PROVIDER.

SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
ORIGINAL BENEFIT DETERMINATION		-4,340.00	-4,340.00	0.00	0.00	0.00	0.00
REVISED TOTAL THIS CLAIM		4,340.00	500.00 ❹	2,289.19 ❺	0.00	20.00 ❻	1,530.81 ❼

THIS IS NOT A BILL

***Learning Opportunity**: ❶ This claim reprocessing from our second insurance company is the result of the months Deb and I spent battling the doctor's office manager, their billing service, and our insurance companies. ❷ Recall the initial denial was dated July 6, 2001. Note that it took <u>three months</u> to get all additional information to the insurance company to reprocess the claim. ❸ In total, it took <u>nine months</u> to ultimately process the first procedure that was performed. ❹ Once paid in-network, this $4,340 was first reduced by $500 not allowed (that became our responsibility). ❺ Then it was reduced again by the insurance RC discount of 59.6%. ❻ Lastly, the claim was reduced by our insurance $20 copay. ❼ The insurance company ultimately only only paid 64.7% of the in-network claim. Yet the doctor stopped Deb's chemo treatment demanding the full list price of $4,340 from us — while she was willing to accept only $1,530.81 from our insurance company.*



[redacted]

EXPLANATION OF BENEFITS

ISSUE DATE	PAGE [redacted]
November 8, 2001 ❷	003 OF 006

WALTER L. CULBERTSON JR
[redacted]

Sequence Number: 000000000
Subscriber's Name: WALTER L. CULBERTSON JR
Identification Number: [redacted]
Group Number: [redacted]
Group Name: [redacted]

Product: [redacted]

Patient's Name: DEBORAH CULBERTSON
Service Date: 05/30/01 - 06/08/01 ❷
Total Billed: $1,541.00

Provider of Services: [redacted]
Place of Service: Office
Patient Acct. Number: [redacted]

ADJUSTMENT SUMMARY
This is an adjustment to a previously processed claim. ❶

THANK YOU FOR USING A NETWORK PARTICIPATING PROVIDER.

SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
	ORIGINAL BENEFIT DETERMINATION	-1,541.00	-1,541.00	0.00	0.00	0.00	0.00*
	REVISED TOTAL THIS CLAIM	1,541.00	0.00	1,176.42 ❷	0.00	10.00	354.58*

[redacted]

EXPLANATION OF BENEFITS

ISSUE DATE	PAGE [redacted]
June 28, 2002 ❸	001 OF 002

WALTER L. CULBERTSON JR
[redacted]

Sequence Number: 000000000
Subscriber's Name: WALTER L. CULBERTSON JR
Identification Number: [redacted]
Group Number: [redacted]
Group Name: [redacted]

Product: [redacted]

Patient's Name: DEBORAH CULBERTSON
Service Date: 05/15/01 - 05/17/01 ❸
Total Billed: $1,390.00

Provider of Services: [redacted]
Place of Service: Office
Patient Acct. Number: [redacted]

ADJUSTMENT SUMMARY
This is an adjustment to a previously processed claim. ❶

THANK YOU FOR USING A NETWORK PARTICIPATING PROVIDER.

SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
	ORIGINAL BENEFIT DETERMINATION	-1,390.00	-1,390.00	0.00	0.00	0.00	0.00
	REVISED TOTAL THIS CLAIM	1,390.00	0.00	753.00 ❸	0.00	30.00	607.00*

***Learning Opportunity**: ❶ Along with the last reprocessed claim for $4,340, these two additional reprocessed claims cover $7,271.00 of the $7,698.56 in charges that stopped Deb's chemo ❷ The top claim took six months from the dates of service to ultimately process and the doctor accepted a 76.3% discount, ❸ The bottom claim was processed in less than two months and the doctor accepted a 54.1% discount. From we her patients, the doctor was willing to accept NO discount!*

Claims Processed	Total Billed	Not Allowed	Patient Savings	Deductible or Copay	Claims Payment	Our Balance
Oct 20	4,340.00	500.00	2,819.19	20.00	1,530.81	520.00
Nov 8	1,541.00	0.00	1,176.42	10.00	354.58	10.00
June 28	1,390	0.00	753.00	30.00	607.00	30.00
❶Totals	7,271.00	500.00	4,748.61	60.00	2,492.39	❷560.0

***Learning Opportunity**: ❶ NEVER GIVE UP! Despite the doctor stopping treatment for $7, 271, we took control of the information. ❷ We only paid $560.*

Nowhere is that old axiom, "You don't know what you don't know," truer than when dealing with Healthcare in America. This is the reason that so many millions of Americans down the road will find out too late and the hard way that their health savings account will dissolve quicker than the money could ever accumulate. All it will take is one episode of being forced "out of network," or the "cash discount" that is not a discount, but in reality, a 678 percent markup over the negotiated price the insurance company would have paid.

As a nation, we must finally address these questions. In our case, what was the real cost, seven thousand or two? I do not have the answer. However, what I can tell you is this. If you are unfortunate enough to have those charges initially denied, and you are in the middle of the complex flow of information between providers, billing services, and insurers, what you will owe will not be the lesser amount that would have been paid in network.

This will be especially true when those bills are quickly turned over for collection while you are still seeking fairness. This reality is far worse than that grocery store. It is why half of our nation's bankruptcies were not only related to healthcare debt but why seventy-five percent of the medical bankruptcy cases were Americans with health insurance.

Cattle Care

As the battle with the financial side of the healthcare system raged, so as well did the battle to get reasonable care from it. During the late spring of 2001, when radiation had concluded, amazingly, Deb felt well enough after the chemo treatments to go to the mall with her mom to stretch her legs from sitting for six hours. Her mom would often bring in donuts and coffee for the patients in the chemo room.

But, as the months wore on, Deb started experiencing severe problems with joint, finger, and toe pain. The ends of her fingers and toes started to swell severely, and her fingernails continued to curve dramatically. The oncologist offered no specific diagnosis and simply stated that was all just part of cancer and chemo treatments. Deb would just have to deal with it and rely on her pain medication. By the early summer of 2001, Deb could hardly move. She could barely get out of bed. While she seemed to be tolerating the chemo treatments very well, the mall-walking trips were over, given the severe pain she was having in her fingers and toes, which even her pain management team could not seem to get under control.

But those were not Deb's only concerns. As each week went by, she became increasingly worried about the chemo process. During the late summer of 2001, I arrived home from a medical conference and speaking engagement to a distraught wife. Deb announced without prelude that she'd had enough. It seemed the nurse who had befriended her during this ordeal was quitting and the oncologist was training another to take her place.

Deb was scared at the thought of a brand-new certified nursing assistant (CNA) fresh out of school taking over the complex job with only eight weeks of training. As we talked, Deb also shared new horrors of which I had been blissfully unaware. Deb's mom had primarily attended to Deb's medical care, while I focused on the bills and keeping up with the demands of my new vice president's position.

I begged Deb not to quit and to give me the chance to go with her to the next session and get to the bottom of things.

"Please, please, don't stop, Baby. Go back one more time and I'll go with you."

I was so confused by what Deb was telling me and could not reconcile what I was now hearing with the seeming trust she and her mother once had in the oncologist. Sure, we had our ups and downs with the oncologist, and at times, she seemed cold, especially at the onset of Deb's treatment. But, generally, she seemed somewhat caring and projected at least the external image that she had her patient's best welfare in mind.

But after that visit, I was ashamed that I made Deb go back. For so many months, I had so focused on the boys, the job, and the bills. I did not ask the kinds of questions I should have about her actual care. This was my first time at the rodeo, as it were. It was my first time standing at the great American Healthcare Roulette wheel. Despite all I thought I knew, I didn't know what I didn't know.

This time I clearly saw that the "chemo" office was old and in disrepair with floors and baseboards that appeared to be worn or not clean. Leveraging my knowledge of HIPAA as an early expert in the new federal healthcare law, I made HIPAA small talk with the staff and the doctor and stood in the doorway and watched. Four patients and my wife were crammed into a single exam room. All were seated armchair to armchair in what appeared to be cloth easy chairs in a room so tight no one could lie back or use the footrest. One unlucky person had to sit in what appeared to be a less cushioned hardback chair.

Pairs of patients shared a single pole jammed in between every two chairs supposedly holding the chemo and other fluids for two patients. I was shocked to see that the doctor used only a simple (cheap) "drip system" with no meters or monitors, and each patient was responsible for monitoring their own bags. Deb had shared that before each session, they were reminded that failure to keep an eye on your bag had consequences. Blood backing up into the tubes, they were warned, would cause a not-so-pleasant flushing procedure.

Even given her outgoing personality, I would learn that one of the hardest things my wife would come to endure was not merely the six-hour procedure. Standing at the doorway, I tried to imagine what it had been like for her all those months being forced into such a small space with no privacy, everyone armchair to armchair, trying to cope with their own fears, their own humanity—having to listen to those who could not be quiet or polite. Even as Deb forged strong friendships with some, she was forced to "deal" with those who were not so pleasant or downright angry for a myriad of reasons including what was befalling them.

But it would also seem Deb performed a valuable role—the pole monitor. Because she was the youngest patient in the group and could stay awake during the long, slow procedure, she would always keep watch on the poles of those who nodded off. Since the six-hour procedure consisted of being filled with fluids, there were, of course, frequent trips to the restroom. When I inquired how they achieved this?

"We remove our bag from the pole and stick it on the bathroom stall wall with a stickpin!"

I could not believe what I was hearing. "What happens if it falls?"

"Oh yeah, after a couple of times of that shit and my bag hitting the floor, I got me a screw hook from Dad and screwed it into the stall wall."

In her typical style, while driving home, Deb would half-joke to her mother about this serious sanitary problem as part of her duty as the pole monitor.

I watched in horrifying disbelief as the routine unfolded as Deb and Jeanne had described. Each chemo day the nurse would come into the room and hang everyone's bag of fluids on the poles. She then laid out on a tray on the counter the port access needles. Donning one set of gloves, never wearing a mask, the oncologist arrived in the room and went down the line of patients. The oncologist dabbed each patient's port with a 2X2 alcohol swab, stuck the access needle through the skin and into the port, and started the flow of fluids.

The doctor never placed any type of dressing over the now-exposed port, only taping the needle down, which made the bathroom routine even more dangerous. Without changing gloves or performing any other sanitary procedures, she simply moved from patient to patient, repeating the procedure. Dab—Jab—Start Flow—Next! Of the oncologist, my wife would ultimately come to ask penetratingly, "How could she have her face two inches from yours, looking you in the eye as she was doing a dangerous disservice to her patients? How could she do that and still sleep at night?"

After starting the chemo, the doctor would see a few scheduled patients, then leave to make her rounds or go to her other office, for the rest of the day. Normally only one nurse worked in the facility with a receptionist, but today there was also the new trainee. While

Deb would often talk about her nurse friend and how difficult it was for her to keep up with so much, until that day I just did not comprehend. Even a seasoned LPN or an RN would have been challenged with such an office routine, much less a certified nursing assistant (CNA) with only limited professional training.

On that day, as seemed was the routine, the oncologist did not return. The CNA would always conclude the treatment and flush the port. While she wore gloves and, unlike the doctor, actually did change hers in between patients, she did not put on a mask. She removed the needle from the port, flushed it with saline and placed a regular "Band-Aid" over the port. As I had seen the bills for so many months, I now saw the dressing billed so expensively to the insurance company. Even when knocked down to the in-network price, that was still one of the most expensive Band-Aids ever made. Again, all this activity was being performed within close proximity of the other patients crammed in a small room with exposed ports, sick or healthy, coughing or wheezing, blowing noses or snoring.

That night my dinner was humble pie. My wife was adamant that she'd had enough after almost eight months of such treatment and worsening pain from her hands and feet. She had enough of the mental torment, enough of the constant battle over the bills. She had enough of the system. For days, I worked to change her mind. I talked and talked. I begged and pleaded. I promised her if she gave me the chance, I would not only get her into another place of care but the best place of care. Through contacts and industry relationships, I was so confident I would be able to accomplish that. Especially with the national industry connections I had formed through my health plan and HIPAA endeavors.

During 1999 and early 2000, I became very involved with the national implementation of the Health Insurance Portability and Accountability Act (HIPAA). Most Americans only know of HIPAA in context of that extra form we have to sign repeatedly at our doctor's office or hospital in the middle of all the other forms that we get handed. HIPAA is often misunderstood by doctors and their staffs and used as an excuse to withhold our information. But if more took the time to read or understand that HIPAA accounting of disclosures form we sign, we would see it contains important information about our rights to access and control our own healthcare data and what steps and measures the law requires of doctors, payers, healthcare claims clearinghouses, and their vendors to secure and protect our personal health information.

HIPAA had initially caught my fancy because of mandated standards for the administrative transactions I had spent most of the nineties working with as I developed and managed healthcare claims and electronic data exchange systems for health plans and third-party administrators. But very early in Deb's battle and living healthcare anew on a much more personal and upfront patient level, I was driven to develop an expertise in the patient protections, privacy, and security requirements that were part of the new HIPAA law as well.

As an early expert in the new law, I volunteered my time to help start and lead two industry physician HIPAA education efforts before Deb got sick. I had no idea at the time how important those relationships would become in the years to come. One such was the bond I formed with Sue, a prominent healthcare attorney from the Boston area. She and I joined forces with Frank, who headed up privacy and security for the American Dental Association, to start and lead a nationally recognized HIPAA Privacy and Security workgroup. Sue would become a most treasured colleague and dearest friend. From the beginning of Deb's illness, Sue created a special card to send Debbie every single day. Each was adorned with not only a motivational message but as an incredibly talented photographer, one of Sue's inspirational photo creations.

In Search of the Holy Grail

But even with such deep industry connections, and having worked closely with health plans, the following weeks proved my promise to Deb to be a tall order. I initially outreached to two out-of-state leading national medical centers of excellence where I had connections. While they did have availability, they would not accept our insurance. Our next option was a medical center in our state and located hours away that had a cancer specialty.

I outreached to the large regional health plan that I thought would have connections with the medical center. I had worked as a consultant on several projects there in the past. I initially contacted

Arnold, a senior executive within the health plan whom I had developed a good relationship with during my previous engagements there. I was fortunate that Arnold took a "shine" to me and appreciated the work I did. I greatly admired Arnold's extraordinary intellect, abilities, and leadership. Every time we got together, at work or over the years with our wives, Deb and Arnold's dear wife, Laura, I learned something new.

Arnold connected me with the health plan's chief medical officer, Dr. Dan, who outreached to someone at the medical center. One week later, Deb had an appointment. Through Arnold's kindness once more, our luck would continue. His organization was in the process of just starting a healthcare technology company with another large health plan to process medical claims, benefits, and information in the new HIPAA standards. I was offered a new job as the chief technology, security, and privacy officer for their startup. Literally, within a week, we went from no hope to miracles. We had a much better treatment place for Deb, and I had a new job that would not involve the travel demands of my current job.

But it had now been several weeks since Deb's last chemo, and it would be several more before we could make the move and get treatment started in a new town. I couldn't imagine how we would continue without having our mom, Jeanne, so close. But we could not stay as is. We just could not.

It was with great reluctance I convinced Deb to go back to the oncologist for at least one more treatment. We also needed to get Deb's records and the formal referral letter we needed. But still, Deb only consented because she wanted to have one more "word" with the oncologist. In her first attempt a few weeks before, the oncologist rebuffed her. In addition to requesting some time with the doctor when Deb made the appointment, she also requested a complete copy of her treatment records.

As we arrived, we were given an envelope with roughly two dozen pieces of paper from the doctor's clinical notes containing only the initial diagnosis writeup and some other summary information. There was no referral letter as we had requested and had been told by the new medical center that they would need. When we inquired, the receptionist shared that was all that had been authorized for release and the doctor was still working on the referral letter.

Hearing the conversation at the front desk, the oncologist discordantly stuck her head out of her office door.

"I do not have time to meet with you today. You will have to arrange another time. I will send the referral letter directly to your new doctor," she sourly and coldly stated, disappearing back into her office.

However, the oncologist knew this was my wife's last appointment. I could not believe Deb held her tongue, but I followed her lead. After chemo was started and the doctor left the building, Deb emerged from the back holding her bag in one hand, and her medical records in her other. She walked over to the copier and I joined her. She softly said she knew if she lost her temper earlier, she would never get the letter or her records.

"Let's just get these and get the hell out of here."

We copied her records while the receptionist and nurse Deb had begged looked the other way. On the way out, Deb stopped and gazed one final time at one of the last stained-glass paintings that she would render before she got sick—a gorgeous bed of violet flowers in the middle of a stream. Deb had hung that many months before in the window of the chemo room. She had said at the time that the other patients needed something beautiful to look at while enduring the long hours in the chair. I asked her if she wanted to take it.

Deb looked around and said, "No. No, those left behind here need it much more than we do."

But even with the new job and the appointment with hope, we would be confronted with our old nemesis—insurance. As one of the first employees of a new, independent, non-subsidiary company in startup mode, we were not big enough to get a group health policy when I first joined. Working for two insurance companies did not change this fact. This could have had devastating consequences, as none of our current medical situations would be covered under the individually underwritten insurance with which small startups are faced.

Even though COBRA coverage comes at a huge monthly cost, in situations like ours, it is often the only insurance lifeline available. More so in our case, as the insurance of the company I was leaving to move Deb to the new town and get her care in a new medical facility, came with the biggest benefit of all—it was in network. Even at a monthly COBRA premium of then $1,100.00 per month, it was still priceless. We had insurance and we were "in network" at the medical center.

I would also quickly learn that in addition to everything else that came with the new job and the new place of treatment and thus hope, we were blessed to have come into our lives one of our most important supporters and someone who would prove to always be in our corner. My new boss, Julie, was one of the most unforgettably creative and talented individuals and leaders I was so fortunate to work with. She supported us with a warm understanding and great heart for what was occurring in our lives and for our sons. Unquestionably, I had a job to do and I did it well, even juggling, as Julie would often say, "so many balls in the air." But Julie afforded me that opportunity through her great caring and workplace flexibility.

I was grateful that Julie also supported my continuing leadership and volunteerism in industry HIPAA and healthcare transformation efforts. Those became important not only to me but to Deb as well. Even early in the war, Deb was already experiencing our healthcare malfunction and complexity. Deb hoped for some change to come about from those modernization efforts.

I do not know how Deb and I would've made it through those early days transitioning to a new town and the start again of Deb's battle without Julie's unwavering support and benevolence, as well as that of our CFO, Margaret. For months, it was just we "three amigos" starting up the new operation. But Deb and I were also blessed with the great caring and kindness of Anita. In between and around her busy executive and administrative support roles working for basically three bosses, Anita still found the time to thoughtfully help us, as did Julie and Margaret in any way they could. We were so truly blessed.

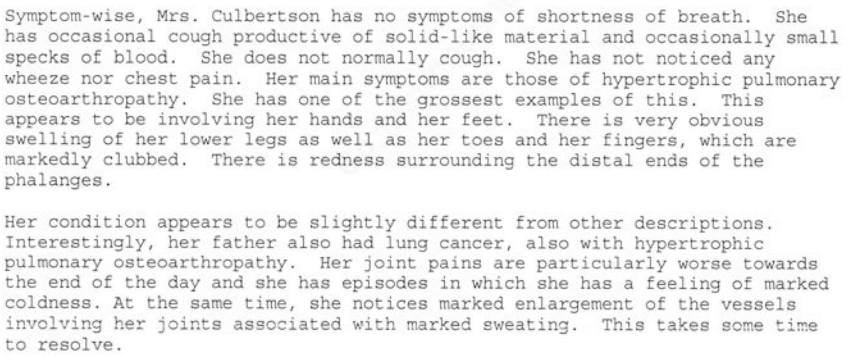
Starting anew the end of summer 2001, as we had hoped, the difference in the quality of care was like night and day. The treatment was even more dramatic than when Deb changed radiologists. It also brought home the reality of just how bad her previous care had been. We immediately felt great confidence in the new oncologist, Dr. Elizabeth. She was kind, she was warm, and she was brilliant. She never rushed, and always took great care.

But then, as Dr. Elizabeth would often proclaim, “All I have to focus on here is the doctoring.”

Certainly, that did not mean Dr. Elizabeth did not have to capture and organize mountains of information. But everything she did was highly automated. At the end of the appointments, while we were still seated in the room, she picked up the phone and immediately dictated her notes and orders. In this case, that included a battery of tests and consultations, including another PET scan. As a healthcare technologist, I was impressed with the workflow. No waiting—no writing—no delay!

More impressive was the news we would hear! Dr. Elizabeth walked through all the records and X-rays we had sent her. As she did, she offered us her judgment. After so many months of no hope and only pain, my wife learned that she might well be operable and not terminal at all. Dr. Elizabeth had only one concern—that spot in the left lung dismissed as “nothing” by the previous oncologist.

We also learned there was a good reason Deb could not get out of bed and why her fingers and toes were so badly swollen and painful. Deb had one of the worst cases of a debilitating bone disease called Hypertrophic Osteoarthropathy (HOA) that even this center of specialization had ever seen. While the disease is rare, it is found most often in patients with late-stage lung cancer. As a former model, my wife chuckled that she would, “again be filmed.” This time, however, it would only be her hands, feet, and ankles for the medical record books.



Symptom-wise, Mrs. Culbertson has no symptoms of shortness of breath. She has occasional cough productive of solid-like material and occasionally small specks of blood. She does not normally cough. She has not noticed any wheeze nor chest pain. Her main symptoms are those of hypertrophic pulmonary osteoarthropathy. She has one of the grossest examples of this. This appears to be involving her hands and her feet. There is very obvious swelling of her lower legs as well as her toes and her fingers, which are markedly clubbed. There is redness surrounding the distal ends of the phalanges.

Her condition appears to be slightly different from other descriptions. Interestingly, her father also had lung cancer, also with hypertrophic pulmonary osteoarthropathy. Her joint pains are particularly worse towards the end of the day and she has episodes in which she has a feeling of marked coldness. At the same time, she notices marked enlargement of the vessels involving her joints associated with marked sweating. This takes some time to resolve.

***Learning Opportunity**: A section of Deb’s clinical notes describing what HOA is.*

We weren't finished learning. In addition to the news about her HOA, Deb painfully listened to a new education about the proper use of her port-a-cath. There was no need for all the pain and suffering from being poked up and down both arms or ankles. They had merely to access the port. All the pain—all the suffering—all they had to do was use her port.

We went from impressed to awed during the weeks that followed. Tests and consultations with specialists, which took months the first time around, were accomplished in mere weeks. The consultations included an array of new members to Deb's medical team. This included a rheumatologist, who prescribed medications that immediately brought at least some relief from the HOA.

Like Night and Day

We marveled how quickly Deb had gone from slow and painful with no hope, to quick, efficient, with all the hope and encouragement in the world. Not more than two weeks after the first visit, we again sat with the new oncologist. Dr. Elizabeth pulled up on her computer monitor the countless tests and images from the scans. What marvels! She carefully and methodologically walked us through the information as she rotated and magnified the images.

When Dr. Elizabeth had a question about one of the results, she immediately beeped the other specialist, in this case, the surgeon. On the other end, he immediately brought up the same image and test result. Together, they looked and confirmed mutual understanding over the phone. This was not merely the vision of real-time healthcare information to which I have been devoted. This went well beyond my simple dream. This was actual healthcare delivery in real time. There was no waiting, no scheduling, and no delay. There was no batching of procedures or discussions to be delayed or lost on another day.

Everyone along the way, including the new surgeon, gave us wonderful news. After months of living with no hope, we were talking about the options for surgery and a good prognosis. However, all this hinged on the outcome of one final procedure—the biopsy results of that one area in the left lung previously dismissed as "nothing" by Deb's first oncologist. If Deb did indeed have cancer in both lungs, surgery would not be an option. We also learned neither would additional radiation. That should have been performed when Deb had her previous rounds of radiation. She missed her chance, it seemed.

The biopsy procedure went far better than we could have ever dreamed, especially considering Deb's first sloppy biopsy experience. This time, the physician and the team made Deb very comfortable. There were no side effects this time, either with the procedure or with the physician performing it.

The beginning of the following week, Monday, the 10th of September 2001, we met with the doctor who performed the biopsy to get Deb's results. As we studied his young face, looking anxiously for a hint of what was to come, he took his time and spoke carefully. It was obvious the task ahead of this new and caring doctor pained him greatly. His eyes became watery and a once-steady and confident voice cracked as he delivered the news.

"I'm sorry to have to share this, but we have confirmed that area in your left lung is cancer."

When Deb asked him what that meant for her treatment plan, the young doctor struggled hard for an answer. Somehow, what came out was that she should take a trip and see places she always wanted to see. On the way home, Deb was at first furious but then started to laugh. "What the hell does he mean to take a trip?"

She knew, though. We both did. We took the news as hard as one could imagine. Still in shock and dismayed, the next day I took off work to spend with Deb. After getting the boys off to school, I served Deb coffee in bed as we continued to try to come to grips with the news from the day before.

"That poor kid doctor took it harder than we did," Deb joked.

As we recounted the meeting, we laughed about how bad we felt for him. Deb was surmising she was probably the first patient he had to deliver such news to. Again, I marveled over her strength and courage. I could not imagine what I would've been thinking had I been the one on the other end of the table the day before. Just as Deb's trademark tenacity and humor started to pierce the veil of the sadness of that morning, the world we were immersed in at that moment changed as suddenly as that trip to the doctor's office the day before.

I was in my easy chair between our bed and a wall of windows looking over at Deb drinking coffee and talking as we contemplated what next. We had the bedroom TV on in the background and occasionally glanced over at the local morning news and events program. The regular show was suddenly interrupted from the local news and weather to a story just emerging out of New York about a possible small plane that had just crashed into one of the World Trade Center towers.

As the minutes unfolded and we continued our discussions, we became more focused on the pictures coming out of New York as the early thoughts of a small plane crashing were quickly giving way to something much more sinister. About fifteen minutes after the first reports, Deb and I had quickly drifted out of our pained discussion that once had dominated and loomed large to the image of the tower with several upper floors ablaze. I vividly remember saying to Deb, "I can't see how a small plane could have caused so much damage," as we watched the live images.

All of a sudden, from the top right corner of the screen, a large plane quickly swooped into view, moving left across the screen and disappearing in an intense fireball from behind the first burning image on the screen. At first, we could not tell where it had hit as the plane had disappeared behind the tower that was ablaze.

As the news anchors quickly shared what we had just seen with our own eyes, they also confirmed what we could not see. The second plane hit the other tower behind the first. Our nation was under attack. In the blink of an eye, as our world had so quickly changed the day before, today it would tragically change far worse for so many others! At the realization of what was unraveling in front of her eyes, it did not take Deb long to come full circle. As terrible as her diagnosis was the day before, she was still alive and was still able to fight. In the sorrowful days ahead for our nation, Deb took stock of it all and determined that was exactly what she was going to do. Fight!

At the next appointment with the oncologist a few days later, Deb told her of the conversation with the young doctor. She then asked directly of Dr. Elizabeth, "What the hell is 'take a trip' supposed to mean?"

With the same care, the same compassion, but steady and calm, Dr. Elizabeth told Deb what we painfully had just started to come to terms with. "I am sorry, but this does mean that you are not operable, given cancer is now confirmed in both of your lungs."

When pressed by Deb about what this all meant and how long she had left based on things as they were in both lungs, with a serious and yet warm expression and voice, Dr. Elizabeth softly shared, "My best guess, and that is all this is, is that given things as they stand today, which can change, you most probably have one to three years." She paused, then added, "Again, things can change and new treatments come out all the time. For now, all we both can do is fight this as hard as we can with the available treatments we have."

Again, it seemed, chemo would make the difference in how long we would have together. Dr. Elizabeth promised to work to keep Deb as comfortable and pain-free as possible. But she also promised to continue to seek new treatments, alternative therapies, and procedures Deb could benefit from.

Dr. Elizabeth then suggested we think about what we wanted, and she would support us in every way she could. For Deb, there was only one course of action. Having been given no hope, only to reclaim it for a few short weeks, Deb refused to give it up again. She had only one word, loud and clear on the way home. "Bullshit! This shit ain't going to kick my ass, I will kick its ass."

Within a week, Deb was back in chemo again for the first time since she was being treated by the other oncologist. As with everything so far, this would as well prove to be like night and day. Instead of being packed into an exam room with four other people, at this new facility Deb had her own room. She could lie down instead of being forced to sit up for six hours, and she could even put her feet up, do whatever made her comfortable. She could watch TV or listen to music. Unlike the non-sterile cloth chair, this chair, along with everything in the room, floors and the baseboards, was polished clean. Stunningly, all this was exactly what the previous oncologist was billing and being reimbursed for.

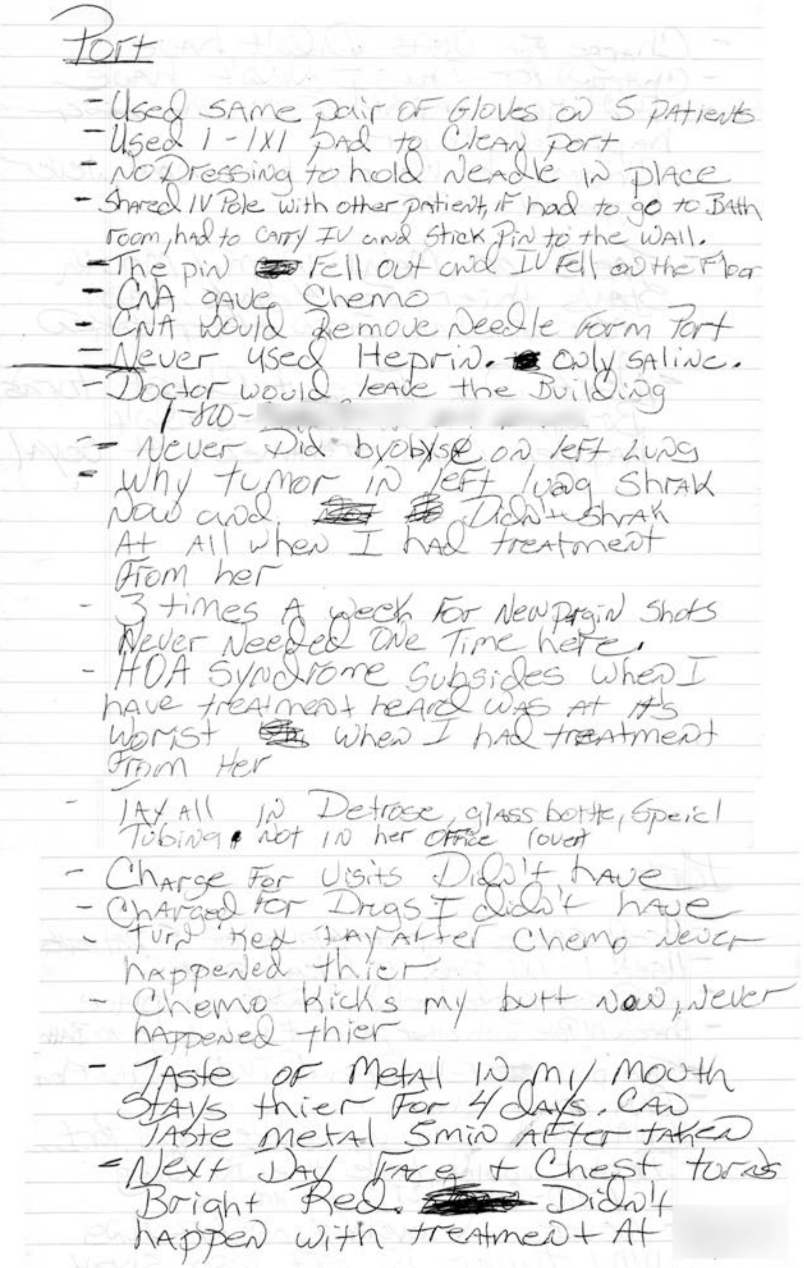
The difference in the quality of the treatment was just as incredible. For starters, the port was handled extremely carefully. The nurses told us there is a strict protocol that states only port-certified nurses and doctors are supposed to access the port, per state law. Further, the port should only be exposed and maintained in a highly sterile environment. But the port could be used for a wide range of needs including doing a blood draw.

All of this great care is because the port-a-cath is directly connected to the bloodstream. In my wife's case, that meant a major vein in the shoulder, just above the heart. We finally saw why the first oncologist had gotten away with billing the insurance company for two-hundred-dollar "Band-Aids" and why she did not want anyone else to access her patient's port. We theorized she must not have wanted her patients to comprehend her inferior work and the great potential for harm. Deb also now understood why her CNA friend always seemed so nervous about what was going on.

At this facility, they used a prepared kit containing all the items that are needed for each individual patient. The first step is to close the door, if possible, to keep anyone else from coming in. Anyone who enters must wear a mask. After washing their hands and donning a set of gloves, the patient is asked to turn away and refrain from coughing. The nurse opens the kit surrounded by sterile padding on the tray and puts on the first set of mask and gloves contained in the kit. The scissors, tape, sterile pads and four sterile foil packages are opened and placed on the tray. Instead of Dab—Jab—Next, the process now takes over ten minutes for each patient.

It was not surprising the actual chemo delivery turned out to be dramatically different as well. Instead of a drip system, the new facility used many different monitors and meters. You could nod off without worrying. In addition to the meters, one RN, certified in ports and chemo delivery, was responsible and dedicated to three patients or fewer. Several doctors also worked in the chemo area and were immediately available if needed, not across town.

At the first facility, all the pre-meds were mixed in a saline bag and dripped into patients via the IV and needle dangling out of Deb's port-a-cath. The chemo bag was simply hung in place along with the pre-meds bag, using the same tubing and was delivered in a saline-type bag, all of which the CNA said the doctor personally "prepared" the night before.



Port

- Used same pair of Gloves on 5 patients
- Used 1 - 1x1 pad to Clean port
- No Dressing to hold Neadle in place
- Shared IV Pole with other patient, if had to go to Bath room, had to carry IV and stick pin to the wall.
- The pin fell out and IV fell on the Floor
- CNA gave Chemo
- CNA would Remove Needle form Port
- Never used Heprin. only saline.
- Doctor would leave the Building
  1-800-[redacted]
- Never Did byobyse on left Lung
- Why tumor in left lung shrank now and Didn't shrank At All when I had treatment From her
- 3 times A week for Newpogin shots Never Needed One Time here.
- HOA Syndrome subsides when I have treatment heard was at it's worst when I had treatment From Her
- lay all in Detrose, glass bottle, Speicl Tubing not in her office (over)
- Charge For Visits Didn't have
- Charged for Drugs I didn't have
- turn Red Day After Chemo never happened thier
- Chemo Kicks my butt now, never happened thier
- Taste of Metal in my mouth stays thier for 4 days. Can taste metal 5min After taken
- Next Day Face + Chest turns Bright Red. Didn't happen with treatment At [redacted]

***Learning Opportunity**: Deb's handwritten notes from the fall of 2001. Deb describes the stark differences between her first oncologist and the new facility.*

At the new facility, the nurse slowly injected several of the pre-meds over ten or fifteen minutes. The final pre-med was delivered via the metered and monitored IV. Then, all the tubing was changed and the chemo (Taxol) is delivered in a glass bottle with special PVC tubing. We were told this was the only way Taxol was supposed to be safely delivered. Instead of a six-hour process, chemo would now be safely accomplished in only four hours.

The results of the chemo were as dramatically different as the delivery and the prep process. There was a marked difference in how Deb's body reacted to the chemo treatment. She had a metal taste in her mouth she never experienced before. From the first treatment at the new facility, Deb would say she "felt like" she had chemo. The difference was so great after the first week, Deb became concerned about her hair. Neither she nor many at the other "institute" lost their hair.

Given all this, early in Deb's new treatment at the new facility, as we sat in a restaurant watching a food inspector make his rounds, Deb would wonder aloud, "How can we invest so much in inspecting the places where we eat, yet totally ignore the places where we receive our medical care?"

It was clear to us that if someone was looking over that shoulder of the oncologist, she could have never been able to get away with putting her patients at such risk.

While the sessions made Deb terribly sick in so many ways that she had never felt before, they had a remarkable effect on her HOA. Chemo helped even more so than the medication prescribed by the rheumatologist. Within weeks, her toes and fingers started to reduce in size and the pain decreased. The change was so dramatic that, at our next visit with the oncologist, Deb asked Dr. Elizabeth what she was giving her.

"I'm certain it was the same as you were getting before."

But, just to be sure, she took the time to turn to her screen and compare the current orders to the now-scanned and indexed documents from the first oncologist.

Dr. Elizabeth turned and said, "Yep! You are getting Taxol, which is what you were given before and at the same dosage."

What Deb would never receive again, much less several times a week, was the painful and expensive Neupogen shots that left scars on her. Even later in Deb's treatment, when her chemo-worn-out blood needed a boost from Procrit, I was allowed to administer the shot from home. There was no time-consuming trip to and from the doctor's office or waste of scarce healthcare resources. Neither the insurance company nor we received a bill for a "doctor's office visit" three times a week for a CNA to administer a shot with no doctor around.

But, unlike before, it was a much-improved routine and process; instead of three to five days a week at different facilities scattered about town, Deb's routine was now just one day a week in the same place. Admittedly, it was a long day, starting with morning blood work and ending with chemo. But everything was accomplished in a single day. We could not get from floor to floor faster than her tests, diagnostic, blood workup, or specialist consult report arrived on the computer of her new oncologist.

This was much easier than being treated through a series of disconnected healthcare providers. The routine made a dramatic difference in the record-keeping and finance side as well. As long as we were deemed in network, our out-of-pocket financial liability was minimal. We received consistently formatted itemized bills, instead of trying to keep up with a dozen or more cryptic provider billings, many of which were unrecognizable. This bill outlined exactly who did what, when, and at what cost.

Over the months, and until the spring of 2002, the treatment and its impacts would continue to be difficult and challenging. Each week, just as Deb started to feel more normal, she would again have chemo and start the cycle over. Week by week, Deb continued to lose weight as she had great difficulty keeping anything down. Days after each treatment she continued to be extremely sick. She had a heavy metal taste in her mouth. This was nothing like what she felt when she was "getting chemo" at the other facility.

No matter what we tried, Deb just had no interest in food as we could find little that would stay down. She was now living pretty much on soup broth, protein drinks, and scrambled eggs. Beyond that, her diet was limited to other things that only occasionally would work with great inconsistency. Some days she could hold a milkshake down, other days she could not.

I became more and more distraught and concerned that chemo was unquestionably now killing her in order to keep the tumors at bay so we could keep her longer. We had many discussions with her wonderful new caring oncologist, Dr. Elizabeth, about the problems Deb was experiencing. She always patiently worked through different options for Deb. But all of the anti-nausea medication being prescribed seemed to have only a limited effect on Deb.

Standing five foot eleven, Deb's weight dropped to under 120 pounds and headed to 115. While she was slender her entire life and typically stayed around 130 pounds, we were now watching as Deb was literally withering away and becoming nothing but skin and bones in front of our eyes.

Through her typical pained humor, Deb would joke she had literally become, "a Cambodian refugee" and "my Wonderbra is wonderin'."

After a particularly difficult session when Deb went to an appointment still sick from the previous week's chemo, Deb was far worse than even typical as the nurse and I tried to help Deb into a wheelchair after chemo. I left Deb with the nurse while I went to get the tribe-mobile and position it at the patient loading area near the entrance. As the nurse wheeled Deb out of the front door, I was amazed to see Deb had a little half-smile on her face. Not only something I had not seen in a while, but also most certainly what I did not expect to see given the scene I had just left in the chemo room.

After getting Deb into the minivan and now waiting to exit the medical center complex at the light at their main entrance, I looked over. While Deb was ghostly white and manifestly sick, she still had an oddly funny smirk on her face.

"All OK, Baby? Let me know if I need to pull over," I said, expecting Deb to get sick as I tried to analyze the look on her face.

Deb let out a half-laugh and then got serious. "I might be OK. How are your pot connections?"

Deb continued to share that as the nurse was wheeling her down to the front door, she had whispered in her ear, "You did not hear this from me, but honey, you need to do something, you can't keep going on like this, or there won't be anything left of you to give chemo to! If you can, find a little marijuana and give that a try. It seems to help others and may help you. But honey, I didn't just say that to you."

While Deb's smirk widened into a smile, I welcomed any idea that would turn the tide against what was now a weekly battle. On the way home, we decided anything was worth a try. It took a few weeks talking to some family and friends who knew some people who knew some people. Having grown up during the seventies, it seemed a great act of sacrilege to be grinding up good pot and dumping it into a brownie mix, despite memories of friends who bragged about doing the same thing.

I could never bring myself to do it back then. But fast-forward thirty-plus years. Here I was, up in the middle of the night, sneaking around so I would not wake up the boys and trying not to get busted. But mostly I was trying not to burn the brownies. While it took me several batches to get the formula down, from the first time Deb ate pot, the results were nothing short of amazingly immediate for her.

Week after week, we stashed the brownies in our bedroom, or that special spot in the fridge, sealed and buried among the vegetables in the drawer that we knew the boys would never voluntarily touch with a ten-foot pole. With the nurse's prescription, Deb was finally able to kind of live through chemo. While she was still very sick, she was able to hold down more of what she tried to eat and her mood dramatically improved. Not only did the brownies stem the tide of her weight loss, over the weeks, she started slowly gaining some of her weight back.

With each week of the routine, Deb was living both the positive and negative impacts that chemo had on her body. From great sickness to great relief from her HOA pain. All this convinced Deb and me even more than ever that whatever Deb was receiving from her last oncologist could not have been the same thing she was receiving at the new medical center. There was just no way.

Back then, after radiation was over and before her HOA pain and swelling intensified and had become debilitating, Deb and her mom used to leave the doctor's office after chemo treatment and Deb could function. She was not deadly sick and often went with Jeanne to get something in her stomach or walk the nearby mall as mental and physical therapy after long stretches sitting in the chemo chair. But now, even given the merciful break she was deriving from her treatment at the new facility from her HOA pain, she was barely functioning because of the new side effects from treatment—debilitating sickness.

No Justice

As the realization of how bad and possibly dangerous Deb's care had been finally sunk in, Deb initially tried outreaching to the state attorney's office regarding her previous care and our suspicions that she was getting watered-down or in some way not real chemo at her previous place of treatment. However, the only advice they could offer to Deb was to first file a complaint with the state medical board.

I contacted Dr. Maureen, a member of the state medical association and a dear physician and HIPAA colleague who helped me establish one of the industry workgroups that I was honored to lead as the founding chair. In my healthcare travels with Deb, we saw the vital need for physician education. Deb was my biggest supporter and motivator. Thanks to my current boss, Julie, I was afforded great flexibility to continue to juggle so many balls, including my industry leadership roles. Putting Deb on the speakerphone in my office, Dr. Maureen patiently listened as Deb described in detail why she needed to put a stop to what she knew was bad care, especially comparing the treatment before and now. She loudly complained to Dr. Maureen her results of the conversations with the state attorney's office. Dr. Maureen asked for a few days to mull over what Deb had just shared with her. She promised us she would help us figure out the best next step to take.

We were stunned when, not a week later, Dr. Maureen gave us her thoughts after the results of her discussions with other colleagues.

"Filing a complaint will take a lot of time to work through the process. And even if they do cite her," she would go on to say, "the process is heavily stacked in favor of the doctor who had no previous complaints. Plus, Deb has no real evidence other than what her body was feeling that she was not being given real chemo. It pains me as a doctor to tell you this," Dr. Maureen concluded, "But your best option would be to get a lawyer, especially as you were misdiagnosed in your left lung and the downstream impact that mistreatment has had on you."

I could not believe I was hearing that word, "lawyer," come from a "doctor." But then Dr. Maureen was no ordinary doctor. She always put the welfare of a patient above all else. One of the reasons I so enjoyed working with her and was grateful she joined in on the cause. I next opened up to one of my colleagues at the state medical association that was also involved in the HIPAA education workgroup I helped start. Fred was an attorney who did a lot of HIPAA meetings and outreach with me. I shared in very specific detail what had occurred before, and what was happening now and the dramatic differences in chemo treatment. Then I shared the advice we had gotten from Dr. Maureen.

Fred patiently listened to me. But he pretty much came to the same conclusion as Dr. Maureen, especially given Deb's misdiagnosis by the doctor regarding the tumor in her left lung that now made her inoperable. He also thought Deb should still file a complaint with the state. "Until investigated, we had no real evidence other than what Deb was feeling in her body before and the difference she perceived now."

Over the weeks, we sadly concluded that dealing with the healthcare battle was enough of a battle. Deb was so sick, and I stretched too thin to introduce yet another professional relationship into our lives. The painful reality was, as we both well knew, suing would not change anything. It would not give us back what Deb had already lost. It would not take away the pain she already lived through. It would not even likely stop a doctor who was mistreating and misdiagnosing her patients.

Around that time, I also had the opportunity to confer with another close friend and colleague, Dr. Jerry. Like Dr. Maureen and Fred from the state medical association, Dr. Jerry was very involved in our provider HIPAA education initiative. Our workgroup was blessed to have such a noted and extraordinarily talented pediatrician and community health specialist volunteering his time for the cause.

Dr. Jerry and I had many discussions of not just HIPAA or our workgroup efforts, but all things Deb as well. Even given his busy schedule and onerous responsibilities, Dr. Jerry was always a phone call away and made the time to talk. Over the years of Deb's battle, Dr. Jerry shared much sage wisdom and advice.

In all my years before or since, Dr. Jerry shared the most profoundly salient observation ever uttered as to why our health system never seems to improve, only getting more complex and costly. In early 2002, Dr. Jerry and I had just finished giving a HIPAA seminar to forty to fifty doctors who, based on their hostility, appeared to be in varying stages of denial to anger to downright pissed off over the impending federal law. We stood chatting in the hospital parking lot, trying not to get hit by any of our seminar participants as they left. Like "oh sure," Dr. Jerry and I wrote that stuff rather than merely attempting to help them and their staffs understand HIPAA and implement it. My only saving grace was they were most probably aiming for Dr. Jerry, because as one of them, he was, after all, a HIPAA traitor. I was just the geek with the pocket protector who started the HIPAA workgroup.

"I just don't understand why those docs in that room didn't get it, Dr. Jerry. The HIPAA foundations make perfect sense, and it's clear why we need it as the industry would not do this on our own."

As typical, Dr. Jerry quickly rendered a diagnosis that was both exactingly clear and thoughtfully concise.

"Walt, there's a simple reason my colleagues in that room didn't get it any more than others in healthcare or Washington or, for that matter, patients. Our healthcare system has evolved to be a thousand-piece jigsaw puzzle whose pieces are scattered in one hundred different rooms. Everyone is sitting in their room looking at their ten pieces of the puzzle thinking that is the picture of healthcare. They don't contemplate nor see how the changes they make to their ten pieces fit into or change the overall picture of healthcare."

Even with all that Deb and I had already lived, I could not have realized the steely foretelling of his diagnosis. I often surreally reflect on that evening conversation with Dr. Jerry standing, of all places, in a hospital parking lot. In years ahead, it would prove to be eerily clairvoyant and translucent.

But as the late winter months and early spring of 2002 wore on, so did the battle, in far more and graver ways. It was inevitable that complications would finally arise. Some medications, indeed, produced wonderful results, such as pain relief without morphine. But as we were warned, drugs can also have serious consequences called "side effects."

Of her pain medication, Deb would often say "the label should say it will cause, not may cause, constipation."

Unless aggressively managed, as we discovered the hard way, some drugs can have grave consequences. Eventually, the medicine that helped so well for the pain from cancer was doing nothing for the severe abdominal pain it was causing from severe constipation. For months, Deb tried everything suggested by her gastroenterologist. She tried over the counter, to prescriptions, to "I heard it through the grapevine."

Deb finally got to a point where we had to make our first trip in a long time to the emergency room. For over ten hours, the staff tried all the same things that we had tried at home at her doctor's suggestion. Deb finally gave up when the nurses came in the E/R room with the news, "The doctor recommends we start from the top of the list again."

They did not want to listen as Deb kept telling them, for weeks, she had tried all the same things they were now doing, and NOTHING would work. They only managed to make her sicker and increase her pain. Her lungs could not take one more episode of being forced to be sick to her stomach.

Much later, we saw the ten-thousand-dollar bill for that one-night adventure. We were charged a thousand dollars an hour for a single CT scan and nurses trying to do all the same things Deb had already done for days herself. That day I was glad to have insurance that was working. But I was also dismayed that neither Deb nor the system achieved a better outcome for all that money.

It also became clear that the hospital serving as the inpatient treatment and teaching facility for the medical center was not as "wired" as the main campus. During the E/R stay, it was apparent the E/R staff did not have access to Deb's medical history. We too quickly had become accustomed to the level of healthcare possible when delivered using health information technology (HIT) efficiently.

The Inevitable

The next day, we saw the other side of Deb's soft-spoken oncologist. Saying that Dr. Elizabeth was not happy about the events of the E/R is certainly an understatement. After she saw the scan from the night before, she immediately had Deb admitted and engaged other specialists. At this point, my wife was severely swollen and nothing was helping the abdominal pain. Over the weekend, the medical team continued to work to provide both pain control and more testing to determine why nothing was working. However, because it was a weekend, it seemed that many of the facilities and doctors they needed were not available. It was an excruciatingly long weekend.

Early on Monday morning, Dr. Elizabeth stopped by and again ordered another consult with pain management. She also verified that the head gastroenterologist would be in to see her. Toward the end of the day, Dr. Phillip appeared in Deb's room surrounded by a group of other doctors. Most were young. All were intently focused on his every word.

At first, it was hard to grasp what the gastroenterologist was saying. Deb was completely impacted and her colon had pretty much stopped working. Dr. Phillip would have no choice but to remove a large section of it. We were stunned. But, as quickly as we got the bad news, with a collective "aha" from the doctors in training around him, we received the good. No, make that miraculous. Even removing two-thirds of that section of her intestines, he would still be able to connect the beginning and the end in a fashion that would allow Deb to have a normal life.

In fact, she would probably "never again experience that bad side effect of the pain medication," he proclaimed.

The gastroenterologist then outlined what he would do and the steps he would take, including getting Deb out of pain. As he feverishly wrote his observations and orders into her chart, many of the new doctors took turns peppering Deb with questions, especially regarding the medication she was on for so long. Through her pain, Deb recounted for them all the other incidents that had been attempted and admonished them to work to, "spread the word to other doctors." By the time Deb was done, the doctors in training were as intent on her every word as they had been on the head doctor's.

At the end of the hour-long bedside visit, the gastroenterologist promised to get things rolling to get Deb out of pain. One minute, we shared a crowded room. The next minute, we were left staring at each other, not knowing what to think. We would later learn we had been fortunate enough to get Dr. Phillip, the head of gastroenterology and one of the best of the best.

But even the best was relegated to using the most ancient of methods for recording and using health information—paper! That hour of watching my wife writhing in pain was far worse than the last time. Deb said over and over this was like delivering two or three babies at once. The first hour came and went with nothing. We had several chats with the nurses cruising in and out to no avail. When I finally went to the nurses' station, the only comfort any could give was to say that, if the doctor ordered something, "It would be on the way."

Almost two hours later, one of the nurses came into the room. We were astounded to hear the reason for the delay—they could not find Deb's chart. They could not find it anywhere. After more time went by, I went down to the nurses' station, making a valiant effort to maintain my composure when all I wanted to do was jump up and down on the nurses' desk and scream at the top of my lungs.

While I was gone, one of the nurses came in and told Deb the good news. They had found her chart. It was in the doctors' lounge on the table. As she asked Deb again who her doctor was and what treatment she was scheduled for, the nurse delivered the bad news. They could not read his handwriting and had to try to reach him to understand his orders. But as my wife was not pronouncing the correct name of her new doctor, the nurse was frustrated and befuddled.

As we passed each other in the hallway, the nurse wore a bewildered look. I stopped and suggested, as calmly as I could manage, to simply contact the gastroenterologist, Dr. Phillip. Get my wife out of pain first, and then worry about the chart. In response, she said they had found the chart and were trying to contact the doctor. As she started to walk away, I watched her as she scribbled in her notes what appeared to be the name of the gastroenterologist I had just given her!

Another hour passed before the pain machines and meters started flowing. In addition to oral pain medication, she was also given Patient-Controlled Analgesia (PCA). Delivered intravenously and through her port, the PCA would allow Deb to deliver her own dose of secondary pain medication. But the pain was so great that Deb self-administered up to the maximum dose every hour. And, every hour, she ran out. She was still in great pain.

Deb kept telling the nurses they just were not giving her enough. During all the battles within her cancer war, she had been on such strong pain meds for so long that she had built up a tolerance. The staff would not listen. Every hour, someone walked in and asked her what her pain level was on a scale of one to ten. Until her surgery, her pain remained eight to ten.

There Are Some Angels

The third week of April 2002, as one would hope from the best of the best, the surgery went off without a hitch. Just as Dr. Phillip promised he would do, he performed a miracle. The surgical report said that what they took out weighed more than a dozen pounds. The pain from the surgery was just as large. It was now off the top of the pain scale. As forewarned, and as it now felt, much of her was either taken out or moved around.

But the doctors never really got Deb out of pain before the surgery. That night was unbearable for both of us, my wife in pain squeezing my hand, I at her bedside helplessly watching my hand turn purple. For hours, every time she would start to go to sleep, Deb would wake up in pain and hit the PCA button. Against the rules, I finally reached down and took the button from her. For the rest of the night, I stared at the clock hitting the PCA button exactly on cue, giving Deb the most I could give her per hour, without her waking up from being in pain.

Sometime in the middle of the night, I heard one of the sweetest sounds I would ever hear, even if only briefly. It was Deb snoring. Early that morning her oncologist stopped to see her on her way to the main campus. Even though Dr. Elizabeth was not the treating physician, and she had a full schedule of patients that day, she still came by. Seeing the great pain Deb was in, Dr. Elizabeth promised she would get one of the heads of Pain Management to come by "STAT."

Not long thereafter, the pain management physician arrived. At first unassuming, obviously very bright, Dr. Todd took the time to listen to Deb's every word and reviewed in detail her pain control history. He actually apologized for the tough time she was having. He also explained that what she was getting would ordinarily have been fine for the type of surgery she had, but not when combined with her cancer history and years of pain management therapy. In addition to other types of pain control, Dr. Todd immediately increased the dosages of what Deb was getting. He also ordered narcotic "lollypops."

Gradually, the pain started to subside. Compared to the ten-plus Deb had been feeling, she was very happy to be at a five. Things were looking good that she would sleep that night, or at least as much as you can, considering how many times a night you are awakened. The first hint should have come when we were told that the pharmacy had overruled the request for the lollypops. Even though we would later get a prescription to use them at home, at this facility, they could only be used on the "cancer" floor. My wife was on one of the surgical floors.

Later that night, the alarm on the pain pump would sound often. As had happened far too often, especially in the middle of the night, the alarm did not receive a quick response. The first time, the PCA-delivered pain medication was not available on the floor. The next several episodes took much longer because it was the epidural pain medication just prescribed by the pain management doctor. It was not standard or readily available on the floor. When needed, it would take the hospital pharmacy an exceedingly long time to deliver. The second time, I begged the nurse to let me go to the pharmacy. It seemed like the medicine was across the country instead of just a couple of floors away. With each episode, Deb's pain not only returned with a vengeance, but recovery would take hours, only to run once again.

The next day, Dr. Todd, the pain management physician, stopped in early and he could not contain his obvious displeasure with the pharmacy and the events of the night before. He really wanted Deb to have the narcotic lollypops. They would have been good for her pain control and not cause any complications from her surgery, as would pills. He wrote special orders, reiterating that her medication had to be kept on the floor at all times.

Dr. Todd would stay very hands-on until Deb was discharged. In the middle of so many other duties and challenges, he took the time. He made a difference in Deb's care, and Dr. Todd provided the turning point. As miraculous as the surgery, so was his care.

After the surgery, we would meet with Dr. Todd many times as he tried to arrive at a non-morphine formula that would work on Deb's cancer pain. He was determined that Deb would not succumb to the pain medication that had cost her her colon. It eventually became apparent, however, given Deb's allergy to morphine, nothing else was going to work as well and that did not make Deb feel sick, sluggish, or buzzed and only worked on her pain, not her mind. As learned through Deb's care, and that of friends and family, the issue of pain control is as daunting as any confronting Healthcare in America.

Stethoscopes and Handcuffs

I would learn much, thanks to Dr. Todd. I spent several days rubbing elbows with pain management physicians from around the nation at an annual conference of pain management doctors in February of 2003. I had easily persuaded Dr. Todd, who was helping organize the annual meeting, to devote an afternoon to the HIPAA legislation. At the conference, I learned firsthand, not only how rare pain management specialists are in this nation, but the startling reasons why.

It may not these days come as a surprise to most, but the medical specialty of treating chronic pain even in the early 2000s was still very much in its infancy, especially as it relates to opium narcotics to treat suffering patients. It was clear even way back in 2003, listening to the presentations and discussions, many of the pain management physicians are themselves wary of providing good pain relief.

But their concerns were about more than just the potential habit-forming nature of some of the pain medications they prescribed. It seemed the treatment protocol was to undertreat patients first and ask them lots of questions later, especially the non-terminal patients. Not only out of addiction concerns as I had once presumed, but also due to realistic trepidation about a knock on the door from the DEA.

Sitting in the back of the room listening to a presentation being given by an attorney, I noticed the seemingly out-of-place suit and tie seated across from me carefully making note of the conversations. He was scouring all the program materials he had gathered. He did not have a conference badge and did not appear to interact with anyone. It nonetheless seemed we both found the presentation intently interesting. Given the repeated episodes of watching my wife and others struggle to obtain pain relief, I was stunned and angry by what was being presented in the session entitled, "The Problematic Patient: Legal Implications and Practice Safeguards."

What I clearly heard was that even back in 2003, our government was waging an aggressive war on doctors generally, and pain management specialists specifically. In the ever-escalating "war on drugs," it seems that physicians have become easy prey for the Drug Enforcement Agency (DEA). Unlike drug dealers who have guns, no office, no records, and nothing much too lose, our government has made doctors the scapegoats in the failed war, not the drug manufactures who overlook obviously criminally overprescribing doctors. Exacerbating an already serious health crisis, the DEA is frightening many physicians away from pain management.

As was reported in New York's *Village Voice* and in hundreds of stories appearing on the Pain News Network website, a resource for doctors and patients, many medical schools caution students "not to choose pain management as a career because the field is too fraught with potential legal dangers." Good doctors are in fear of finding themselves being unfairly stigmatized and as labeled as their patients. Given that one prosecutor then had promised to root out bad doctors "like the Taliban," it is easy to see why patients are facing a pain crisis. I wonder how quickly law enforcement would have leapt into action when we called about Deb's first oncologist, who we strongly suspected was not giving her real chemo, if we would have been reporting overmedication of pain drugs, rather than under-medication and dangerous delivery of a life-saving drug?

It is tragically American that a one-sided media campaign reinforcing addiction stereotypes, and congressional demands for a return on the investment for the failed drug war, is fueling a care crisis that is forcing many Americans to needlessly suffer. Even in the face of overwhelming medical evidence that opioid therapy rarely results in accidental addiction or abuse among those who <u>really need and rely on the medication</u>, such as cancer patients, we are allowing the DEA to determine how patients are treated and relieved of their pain, or not.

Unquestionably, the greed-infused propaganda of the pharmaceutical industry has encouraged physicians to prescribe pain medications that were promoted as safe and less addicting. Today, we know the truth was not completely as advertised. Through hundreds and hundreds of millions spent in advertising, drug manufacturers have become little more than drug pushers targeting undereducated doctors and the unsuspecting public and further propelling drug use among the American public with very real consequences.

But while our nation does indeed have a crisis with drug abuse, as well as some bad doctors and pharmaceuticals who only want to make money, innocent patients in pain suffer when we try to overcorrect the problem instead of dealing with solutions that get to the root of the problem. Many of the challenges with prescription drug abuse are born out of our insane war on drugs. Not all those abusing pain pills are former patients that got hooked on pain meds from that prescription from their doctor. Certainly not all, but many, are those running away from life or poverty or those that through biology or other social factors became easily addicted.

Without question, Deb was dependent on the medication that cost her her colon. Without the medication, Deb would have been completely incapacitated by her pain and could not contemplate a functioning life and thus having a life at all. But her pain medication did not give her a high or make her crave more of the drug to obtain a high. Deb did not live for each pill or take more and more of the medication because of an addiction. She was living the natural act of being in pain and seeking relief from it.

I doubt there are many law enforcement agents who clearly understand this distinction, which for them is merely a nuance. Sadly, however, it seems as I sat in the back of the conference room that day listening to the Q&A between the lawyer and the doctors, even physicians have fallen victim to the “addiction” versus “dependence” confusion.

Even more astounding, however, these were “pain management specialists.” I also now understand why, when the gentleman seated across from me in the back row got up to leave, not all of those attending the conference were doctors or, like me, HIPAA wonks. As he stood up after the session and bent over to pick up his conference tote bag of goodies, I got a quick glimpse of what clearly appeared to be the outline of a firearm holster in his suit jacket.

Proving today’s opioid crisis could be seen coming for miles, even all those years ago, there was extensive media attention given to those classes of drugs. At times, it became difficult to acquire even back then. Those really needing it were ignored amid the fervor of concerns regarding inappropriate recreational use. Given how well the pain medication worked for my wife and how normally it allowed her to live, it was hard to comprehend the hype around it. Deb was an example of those who really depend on it for pain and not getting high.

So many times, Deb ran out and could not obtain her pain med at our local pharmacy. Many times, even driving all over our end of town with so many pharmacies, it was difficult to find. Complicating the matter was that we simply could not just go to the pharmacy. We could only go to the pharmacy in the network of our insurance company.

Even when we were not turned away at the pharmacy, many times Deb had to settle for what they could dispense. As the insurance would not allow a refill until you are almost out, Deb was always at risk. Hearing the pharmacist say we have an order arriving on Wednesday or Thursday is no comfort when you are standing at the window on a Monday.

As May of 2002 unfolded and in the caring hands of Dr. Todd, joining those of Dr. Elizabeth, Deb was back on her original pain medications and healing slowly from her surgery. Dr. Elizabeth gave

Deb the green light to begin her chemotherapy routine again. But over the weeks that followed, it became apparent with each chemo session, Deb would not just simply go back to where she was before her colon surgery.

Chemo was now having an even more devastating impact on her body. Each time Deb underwent treatment, she could barely make it out to the parking lot before becoming violently ill. Dr. Elizabeth was trying everything she could think of. So were we. Even Deb's magical medical brownies were having no impact as Deb was having great difficulty holding anything down and started to drastically lose weight again.

Caught Between a Rock and a Hard Place

Could Not Go Back

Throughout May of 2002, Deb's chemo sickness made everything dramatically worse. The unmerciful side effects of her inability to keep food or liquids down were in not only starting the cycle of weight loss again, but also the constant sickness wreaked havoc with her pain management. We had many consultations with Dr. Todd, he including many over the phone in an extraordinary act of care and kindness in not forcing Deb to come into his office. When Dr. Todd had a jammed day, as most seemed to be, he did not put Deb off. Instead,took the time in between patients or at the end of an already long day to call us back, even at night.

Even through rush-hour traffic, or another obstacle, work-related or otherwise, I thankfully made the trip over to his office to pick up any new prescriptions and deliver to the pharmacy. Working closely with Dr. Elizabeth as a coordinated team, they collaborated on trying everything in the books, yet collectively they had a difficult time keeping Deb's nausea and pain under control. There were also many instances when they had to collaborate to do battle on the other side of healthcare, spending their valuable time battling the insurance company trying to get authorizations for the treatment they were trying to prescribe.

But little seemed to help during the new rounds of chemo and

Deb was now almost bedridden. In the middle of the summer of 2002, Deb made the most difficult and devastating decision of her life. As we sat with Dr. Elizabeth and talked about any available options we had, we seemed to have run out of options. They only thing that would keep the tumors at bay and possibly not spreading was the chemo that Deb's body was no longer tolerating and in fact, was violently rejecting.

For the first time in her two-and-a-half-year battle, given all the torturous events and pain she had already lived through, much less what was happening to her now, Deb finally succumbed. That evening I awoke in the middle of the night to find neither Deb nor our German shepherd, Mich, in the bedroom. I walked into the front room and found Deb sitting in her chair in the dark. Mich was dutifully lying by her feet.

Deb was bent over with her head in her hands, crying and sobbing as softly as she could. I walked over and hugged her while she continued to cry into her hands. Then it all came out of her. She could no longer stop or hold back the waterfall of tears. She was crying so hard she could not talk. I sat down near her, putting my arm around her. I was so hurt and broken. In the twenty years that I had known my tough Chicago girl, I had never seen her like this. Nothing I can form into words can express the emotions running through me as I sat next to her. I knew before I finished the words flowing out of my mouth as I put my hand on her leg and leaned forward as close as I could get, that not everything was OK. I was asking stupid questions. Nothing would ever be OK again.

"Hey, Baby. Is everything OK? Did you wake up in pain again? Is there anything I can do? Please tell me. What can I do, Baby?"

At the sound of my voice, Mich sat up and rested his chin on Deb's leg. When she did not respond, he got insistent that she acknowledge him and started to stand, pushing his head more firmly into the back of her hands as she continued to cry and sob into them. Finally, Deb took her head out of her hands and reached out and gently started petting Mich's head. He knew Deb was distressed. I cannot just share that he was an amazing dog. Mich was much more than that. He was an amazing member of our family. He was the intuitive member. He was "the" protective member. Mich could always read us like a book.

Unquestionably, the last couple of years were as difficult on him in many ways as the rest of us. Our once-steady family routine had been set on its ear. We had moved two times in two and a half years trying to get Deb the best care we could. One of the most difficult conversations Deb and I had at nights were those as she recounted her torturous childhood memories.

"No child should have to live through this," she would say countless times.

It was her family, including Mich, living through the nightmare. In his intuitive, uncanny canine way, Mich knew that something was wrong with Deb before we even did. In the months prior to going to the first oncologist, there was a distinct change in Mich's behavior. We both noticed this and mentioned it to each other many times. Mich started staying more closely glued by Deb's side throughout her daily routine. Many days I would come home and he would uncharacteristically not be in the foyer by the front door waiting for me. There were even times he did not immediately jump at the opportunity to go for our nightly walk. He seemed to always be underneath Deb's feet, and we even started wondering if there was something wrong with him. But looking back, Mich knew Deb was not well, and he was displaying it in his clinginess.

Finally, Deb's words pierced the sound of her tears, and she started to pull herself together, and once the tears stopped, she collected herself and the thoughts that were flowing through her mind at that moment. With all the strength and determination that she had always shown throughout our time together, I was not expecting what was to come next. She took both my hands, pulled me closer to her, and wrapped her arms around my neck and kissed me and kissed me again. Then she sat back in her chair and looked around the room, finally resting her gaze back at me.

"Enough is enough. Enough is enough. I don't want to give up. I don't want to surrender to this shitass disease. But I can't continue like this. I just can't."

She softly started crying again. "I won't. I am so sorry. So sorry I can't find it in me to keep doing this shit. But I can't."

Putting her hands in the air and clenching her fists, she added, "I can't stand the sickness and constantly throwing up. I can't stand fighting the insurance company to get shit approved."

She got silent and sat forward, pulling my face to hers, looking into my eyes as she held my face tightly.

"The way I feel right now, I can't stand living. Can you understand that?"

I didn't know what to say. Living through all of this with her, and especially the last couple of months, was so difficult. So painful.

All I could say was, "Yes. Yes, Baby, it kills me, it does to say this, but I do understand. I so do."

Since day one, we did everything we could to shield our sons from as much of what was swirling around us as we could. But we could not stop Thomas and Steven's world from being completely upended. Of all the worries and things that we talked about and discussed that evening, almost all the focus after Deb shared her decision to stop treatment, was on our sons and how we would tell them and console them and prepare them.

Throughout it all, Thomas and Steven continued to display great strength and were a source of not only great pride but also a source of great comfort. With everything going on in our lives, the one thing we never had to worry about were those boys, whether it was getting themselves up and off to school, or coming home to an empty house. They never once got into serious trouble, including those times Deb was in the hospital.

The more the battle raged, the more I watched the care Deb was not receiving in the hospital, the more I felt compelled to be there with Deb as her patient advocate. Our sons allowed me to be there with their mom because we never had to worry about them on their own or otherwise. We marveled over their maturity and strength and we were so thankful for it and so very proud of them.

Thomas and Steven had such a difficult start to their teenage years despite our best efforts. Even so, Deb kept looking at our sons, more so lately, sending her into a downward spiral of reliving her painful childhood, clearly knowing even more than I did what our sons were going through and what they were thinking. The torturous childhood journey she lived that seemed to have changed little over all the years—despite all the proclamations of how Healthcare in America had advanced since then.

But the facts were harsh. Deb was so right. Children should never have to live through this. Life can indeed be so unfair. While Thomas and Steven's friends celebrated the start of their teenage years, our sons were spending theirs living a nightmare. So many nights and evenings watching their mom leave the dining table and rush to the bathroom. There were so many other nights when their mom was not able to even be at the dinner table at all, not able to make it out of bed. Those times they had to see her in the hospital after surgery. Watching their mother in pain and hooked to all the wires and mechanical devices.

Deb and I stayed up the rest of the night talking about our sons and her decision. We agonized over the future, or lack thereof. We discussed the need and the importance of addressing Deb's decision to stop treatment in the best way that we could with our sons and her family, especially her mother, Jeanne. Deb was worried her mom would not understand. But the more we talked, we both agreed how could our mom not understand given all she had been through in her own life as well. All that we both knew Mom was living inside, watching her daughter go through all the same things her husband had.

The middle of June, Jeanne was getting ready to pay us a visit for a trip I had to make out of town. Deb knew she would get her chance to have that discussion with her mother face-to-face. My trip the following week was for the provider healthcare education workgroup I chaired. We were having our quarterly meeting in New Orleans.

Listening to Deb's decision that evening, I proposed my own decision.

"Well, Baby, I am going to cancel going to the meeting next week. I also have been thinking about this for weeks and all things considered, it's time for me to step down from the leadership reins and limit my involvement with those groups."

But Deb would not hear of either of those thoughts. Given all the things we were living through, those roles became as important to Deb as they were to my day job. Deb would often quiz me on what we were doing and pushed me to do more. We were determined, even if only in our own small way, to try to help bring about change in healthcare for doctors and in turn their patients. Deb was especially interested in efforts to help patients get copies of our records for our own files. That always proved to be a daunting and sometimes expensive challenge.

But among the most maddening and scary, were the challenges with doctors or pharmacists trying to get preauthorization, and insurance companies making the right call that you are covered and getting the claims correct afterward. Finding yourself in a mind-numbing position—being handed a medical bill you can't make heads or tails out of, or a bill that is bigger than any amount in your bank account.

As we talked further, Deb decided a father-and-son road trip was the way to get the conversation started with our sons. She would have some alone time with her mother. I would not only make that meeting but also take two volunteers with me. I packed up the Caravan, our tribe-mobile, as we referred to it, and all the way to New Orleans talked about everything under the sun. But I avoided discussing what was happening with their mom. I decided as the miles wore on to make their time in New Orleans a well-earned adventure and respite. I would save the discussion regarding their mom for the trip back home.

Over the next several days, my wonderful workgroup colleagues made the newest members of the team warmly welcome. They were attentive and supportive from day one. I was blessed in so many ways to receive such caring and kindness. I drew great strength from the encouragement and support of such kind and thoughtful colleagues-turned-friends.

The HIPAA and healthcare transformation workgroup had been started just a couple of months before Deb was diagnosed. I was having lunch at a national HIPAA meeting in Arizona and was fortunate that day to be seated at a table with government and other private industry experts from the south. Dr. Maureen was in private practice in one of my state's largest cities. Cathy was a senior manager from the regional office of what we know today as the Centers for Medicaid and Medicare Services (CMS). Gil was a senior manager from the Health Resources Services Administration (HRSA), the primary federal agency responsible for improving care for people who are geographically isolated, or economically or medically vulnerable. I was greatly inspired listening to Gil and Cathy. We are truly blessed as a nation to have such talented, caring, and dedicated public servants.

Discussing the monumental implementation challenges of the new law, especially on smaller physician practices, and brainstorming what we could do, we centered on the idea of establishing a public/private workgroup and collaboration of engaged stakeholder organizations. Our mission would be to provide medical communities throughout the South with free HIPAA education and training that served to help address some of the unique implementation needs of the Southern region.

My dear workgroup colleagues were aware of what was happening on my home front as I often shared the ups and downs of our personal battle as ammunition for the cause. But I decided not to share the latest news or the real reasons my sons made the trip with me. Everyone took Thomas and Steven under their wing at the meeting. Cathy and Gil, who were our workgroup co-chairs, led the way with a number of the steering committee and other members contributing above and beyond the call of duty for a normal business function. There were so many other dear colleagues I was also thankful for including; Dr. Maureen, Dr. Jerry, Jim, Roger, Michele, Sara, Glenn, Martha, Michelle, Brenda, Kent, Kathy, James, Dr. Sybil, Mary, Adam, and many more.

I can still hear that "wow" the boys let out when we pulled into the original Iberville Suites in the French Quarter where the meeting was being held. They had never been to a downtown hotel, only cookie-cutter hotels in standalone buildings. Thomas and Steven were amazed at the hotel and the lobby and were thrilled with the suite we had. They helped Cathy, Gil, and me set up the meeting space and each day had a few assigned tasks that were given to them including helping to set up for lunch. When our workgroup was in session, Thomas and Steven had their fun between room service, on-demand movies, playing video games, and swimming in their first indoor pool. But other than room service snacks, the boys had their meals as part of the workgroup team.

I beamed with pride at how well my sons behaved and grasped the lunch and dinner discussions and so comfortably interacted with everyone. I marveled again at their maturity at ages thirteen and fourteen. So did the team. When we ventured out at night along the French Quarter and some of the other sightseeing group activity, Steven and Thomas were not only in tow, they were part of the team. Many even joined in when the boys and I went to the Aquarium and IMAX to see a new Star Wars movie that had just come out at the time.

Among our other memorable side adventures was the meal we had at the House of Blues Restaurant and Bar. Also, the extremely apologetic hotel valet who backed our tribe-mobile into a pole and the rear window shattered. We did not have time to fix the damage in New Orleans and drove home with plastic covering our rear window, making for a noisy drive home.

But I will confess, as they did to their mother, the adventure within all the adventures turned out to be the early evening stroll we took down famed Bourbon Street with a few of the team. I would have never guessed things got started so early! One of the team would even comment the boys were better than puppies at a park in attracting the ladies—go figure. Thomas and Steven proudly collected lots of beads to present to their mom. That, of course, led to my having an interesting discussion with Deb about my choice in sightseeing activities.

I learned much from that trip and the hours of discussion on the way home with my sons. Mostly what I learned was the strength and courage of our two young men. After having my discussion with our sons about what was happening with their mom, things became silent in the minivan and after we stopped for something to eat, they drifted off to sleep.

I am not certain which mile marker it was, but somewhere along the way that evening, reflecting on it all and looking next to me and in the rearview mirror at the results and examples of Deb's Dutch determination, it was my turn to get some. We arrived home late to Mich greeting us at the front door. Deb was fast asleep and Jeanne had left earlier in the day to return to her own very busy life on the road with her husband, Ken.

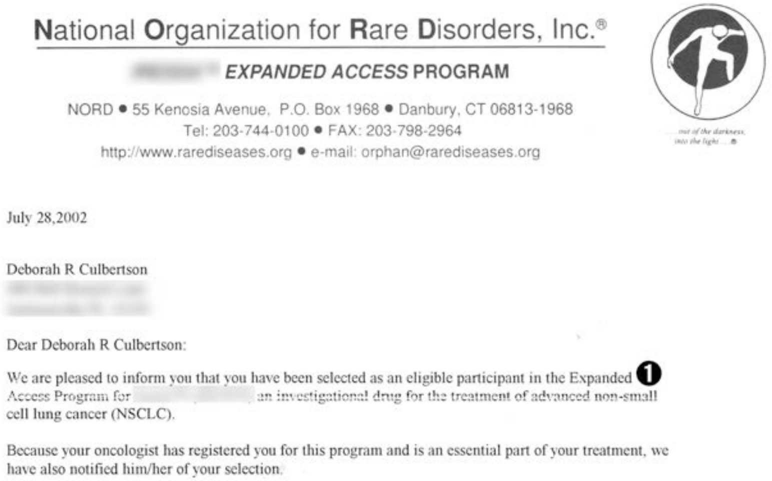
Ken was a construction superintendent for Walgreens, in charge of building new stores all over the nation and Puerto Rico. Once built, Jeanne helped set the store up and initially stock the shelves, and got the store ready for the grand opening. They made a handy team for lucky Walgreens. They had a remarkable partnership and marriage. Words can never adequately express my thankfulness for them being in our lives and all they did to help support us in life and Deb's battle, oftentimes at great inconvenience, costing them their own challenges and hardships. If we could not count on anything else, we always knew that whenever or whatever was needed, we could count on them. I was so fortunate that when Deb came into my life, so did the most loving and caring Mom and Dad. So blessed was I to be able to have Ken and Jeanne as my parents, and grandparents to my sons.

I was so heartbroken for Jeanne. I could not imagine all that was going through my other mom's mind as she watched her daughter. Especially given all Jeanne had lived with her late husband Ray, Deb's father. There were so many parallels—with not only the disease and its progression, but also the seemingly inevitable battle swirling around the disease. Jeanne long before had shared that even while they went broke and lost everything, including the father of her daughters, she was lucky she was working at a doctor's office at the time.

A doctor who went out on a limb for her, not only helping to give her a job but also helping her to be able to acquire the medications her husband needed when she had nowhere else to turn. One of the biggest things that so haunted and tormented Deb during her battle was everything that she was living was exactly the way it seemed to be back then. Over all the years, the healthcare system of the greatest, most prosperous nation on planet Earth had cruelly not changed very much at all. Especially as it was now she and her family trapped in the middle of our own war trying to pay for battle and battle.

With these and so many more torturous thoughts swirling around and through me, I snuck into our bedroom trying not to wake Deb and lightly kissed her on her cheek. I decided to get busy in the early pre-dawn of that Saturday morning. I unloaded the tribe-mobile and took Mich for his own well-deserved break—a long walk around the neighborhood collecting my thoughts. I spent the rest of the night on the Internet.

The next morning, I poured the coffee and shared the highlights of our trip, while the boys, of course, elaborated in more detail, presenting their mom with the beads of evidence! I, in turn, presented Deb with my research and some of the things that I had found for treatment possibilities. Of all those options, the most promising was a new class of drug being used with great success in Europe and Japan. Deb agreed. At her next appointment with Dr. Elizabeth, we discussed again Deb's options. Within a day, our doctor angel found a clinical trial that was being performed in our state in a town three hours away, and she quickly got Deb into the program. Deb started her new treatment regimen, a pill-a-day, a month later.



National Organization for Rare Disorders, Inc.®

[redacted] *EXPANDED ACCESS* PROGRAM

NORD • 55 Kenosia Avenue, P.O. Box 1968 • Danbury, CT 06813-1968
Tel: 203-744-0100 • FAX: 203-798-2964
http://www.rarediseases.org • e-mail: orphan@rarediseases.org

...out of the darkness, into the light...®

July 28,2002

Deborah R Culbertson
[redacted]

Dear Deborah R Culbertson:

We are pleased to inform you that you have been selected as an eligible participant in the Expanded ❶ Access Program for [redacted] an investigational drug for the treatment of advanced non-small cell lung cancer (NSCLC).

Because your oncologist has registered you for this program and is an essential part of your treatment, we have also notified him/her of your selection.

Learning Opportunity: ❶ *NEVER GIVE UP! Deb's clinical trial acceptance letter!*

Once again, we had gone from no hope to have at least a chance. During the months that followed, however, the bone disease (HOA) that was helped greatly by the chemo regimen was starting to rage again. Over the next year, as the toe and finger swelling and pain grew, one by one, Deb would go through all of the Cox-2-type drugs that were hotly being debated at the time. After many months, each did little for the bone and joint pain. Each had dramatically different side effects that were of an issue with that class of med. Interestingly, the pill that helped the most was simple ibuprofen. At this point, Deb was also taking the maximum doses of her pain medications. But this once again proved to Deb that she was not getting "real" chemo from her first oncologist. It was clearer than ever that "real" chemo abated the HOA.

But as the summer of 2002 came to a hot and muggy conclusion and our sons started back to school, we had another family crisis on our hands. Suddenly, over the span of just a few weeks, there was a distinct change in our Mich. He became lethargic and seemed to have great difficulty getting up and moving around. We knew something was seriously wrong with Mich when he was no longer eager and excited for his walks or to play Frisbee. We took him to his wonderful young vet, Dr. Rod. During Mich's last checkup just six months before, he was the picture of health, even for a nine-year-old German shepherd. So the vet was greatly alarmed about Mich's rapidly deteriorating condition. At first, the prevailing thought was, given his age, perhaps arthritis was rapidly setting in.

But after the X-rays, it was very apparent something was seriously wrong, and even our own vet did not understand quite everything that was happening. The vet saw things on the X-ray with Mich's internal organs that just did not look normal. They recommended that we immediately take Mich to an animal hospital and have them provide their thoughts about what was seen on the images. The animal hospital was equally perplexed. They decided that the only course of treatment was to try to do a costly exploratory surgery to look inside and determine what was happening and why Mich's organs did not appear normal on the X-rays.

The look on Mich's face as they put the leash on him and took him into the back and how afraid he was, still haunts me to this day. Deb and I begged the staff to let me stay with him but of course, I could not. The staff shared it would be an hour or more before they could even get him prepped and ready for surgery and suggested that we perhaps grab lunch somewhere as it was approaching noontime.

They promised they would take the greatest of care. Deb already had an upset stomach with worry about the family member who was a core part of our lives. So rather than sit or, in my case, pace around the waiting room, we decided to go to a nearby restaurant. On a Friday afternoon, everything was crowded and it took a long time for us to get a seat. Our food had just arrived when the animal hospital called. Given their original time estimate, we were surprised.

I was stunned as I was hearing what was being shared on the other end of the phone. Deb saw the look on my face and immediately started softly asking questions.

"What's wrong? What's wrong with our Mich?"

Mich was still in surgery and on the table. What they described was Mich's major internal organs were hardening from the inside. He had a rare condition that even the doctors on staff at the animal hospital had not seen before, "some form of systemic sclerostenosis." The only course of treatment to keep Mich from suffering was to put him to sleep. With the animal hospital still on the phone, I explained to Deb what was happening.

We asked if we could go back and see Mich before they put him to sleep. But they shared that even if they closed Mich back up so they could bring him out to be with us, he would be heavily sedated and would not even know we were there. They strongly advised, all things considered, the most humane thing to do as Mich was still on the operating table, was to go ahead and put him to sleep.

Not since the night Deb had first made the decision to stop chemo had I seen her so literally broken apart. While not a long ride in terms of miles, it became a forever ride getting back to our home. The boys had just gotten home from school and noticed that no one was home. When we walked in the door, Thomas and Steven saw a sight that even given everything their mom had lived through at that point, they had not seen before. Crying so hard she could not even begin to say a word to them, Deb went immediately into the bedroom and closed the door.

I had another very difficult discussion with our sons. So much swirling around us, including the possibility of still losing their mom, the boys tragically learned about the absolute fragility of life. How quickly things can change. When they left that morning, Mich was still alive with no thoughts of what was to be. In the space of the time it took them to go to school and return home, Mich was forever gone. They took the difficult news very hard and did not understand at first why they could not have said goodbye to him. Then once explained, they wished they had spent more time with him before they rushed out to school that morning. A painful life lesson about the regret of never knowing what could happen next in life. Never knowing when that which you love could be forever lost.

The next several weeks were difficult as Deb was badly shaken by the loss of Mich. Even a visit from her bestie, our dearest friend

Linda, did little to pull Deb out of her doldrums. But shortly thereafter, the boys and I would arrive home at the end of a day, and at the dinner table, we could tell Deb's mood and distress was much improved. Then, to our great surprise, Deb shared the reason why. She made up her mind that she immediately wanted to get another German shepherd and she wanted me to find one, "Now!"

That October 2002, still not knowing how or whether the new cancer pill would help and with everything else in our lives looming over us from the battle, I tried to talk to Deb out of her decision. Having grown up with German shepherds and their puppies and having them throughout most of my life, there was no one that wanted another more than I did. But I was very concerned about the timing. I well understood the other side of having a large extended family member like a shepherd. How could we train and raise a puppy into adulthood with everything swirling in our lives? But I suppose the biggest reason I did not yet want to contemplate a new shepherd was I was still badly grieving Mich. I simply was not ready yet.

But timing be damned! Deb was determined. She wanted what she wanted and there was to be no talking her out of it. Spending some time after dinner on the Internet, I saw no options in our immediate area. But in the next state over, I did spot an ad from a breeder who lived on a farm. He had just that day posted the Craigslist ad with some adorable pictures of seven, six-week-old puppies. They were amazingly all sitting calmly in a row looking at the camera. Deb took one look at the picture and then gave me the look. That special Deb look. Without commanding me to call, she was.

When we got the anxious breeder on the speakerphone, he said if we liked one of the puppies, we could even take it home with us right away. He sold puppies at six weeks all the time. At that, Deb insisted we set the time and hit the road in the morning. Saturday the boys jumped into the tribe-mobile and even Deb had a spring in her step that I honestly could not recall when I had last seen. They talked with excitement all the way there, which made the three-hour drive to the farm over before I knew it. All the way, my mind was still on Mich.

Looking at the glow that had returned to Deb's eyes, and trying to set expectations, I did my level best to give Debbie my advice based on my experiences. My parents raised puppies for a time growing up, and we would never let a puppy go before eight weeks. The most Debbie would commit to at that point was, "we'll see." I was dead-set that I would have to disappoint her and the boys. Even if we found the right puppy, we would not be driving home with it that day. If we saw a puppy we liked, we could pay for it and leave it with the mother for another two weeks. Yeah, right.

We arrived at the "farm" to a home that was old and in need of some repair and paint. A younger man was standing in the front yard wearing shorts, a tank top, and good-old-fashioned cowboy boots. As we pulled in, both Deb and I said almost in unison, "This ought to be interesting."

We were surprised he was much younger than he sounded over the phone. His wife, who appeared to be a touch older, came out and joined us dressed in interesting attire as well. Wardrobe aside, they turned out to be a very nice and well-spoken couple, demonstrating you can't always judge a book by its cover. After we introduced ourselves and made small talk, they commented we were first to respond so we had our choice.

His wife went back inside and appeared with a puppy in each arm. The "oohs and aahs" commenced. Making several trips, she assembled all of the puppies in a fur pile on the front porch. All were varying combinations of black and tan. Straight away, Deb and the boys were drawn to the biggest puppy in the litter—a male almost twice the size of the rest with a white star on his chest. He was the most rambunctious and playful, lacking any shyness at all. As Deb beamed, the puppy was all over the boys. Deb and I picked up some of the others. All the puppies were adorable. However, the big guy melted all of our hearts. Mine included.

The last step was to examine the parents. Deb and I walked around back to the kennel while the boys continued to immerse themselves in puppy heaven. The father of the litter was large at around ninety pounds with perfect black-and-tan saddleback markings. But when he brought out the mother, Deb grabbed my arm hard and we both let out a gasp. The female was black and sable and a perfect smaller clone of our Mich. Unlike the standoffish male, the female came right over to us. As we petted the female, our gaze alternated between each other and the mini-version of our Mich.

Without saying anything, Deb and I knew, looking into each other's eyes, this was meant to be. I also knew as I stared into those blue eyes sparkling as I had not seen in so very long, there was no damn way we would be driving back home without a new family member. When we walked back around front, the boys ran over to us with both trying to hold the large male pup at the same time.

Alternating shrills of, "can we have him" and proclamations they would, "do anything including taking on more chores to have him."

During the ride home, Deb cradled the puppy in her arms, trying to keep him from whining. The fun of taking him away from his mom and siblings had just begun. I knew at six weeks old—even more fun. Everything happened so quickly, we had not yet firmed up a name for the newest member of the tribe. As we took turns kicking around names, Deb threw out the name "Cody." Everyone in the tribe-mobile instantly blurted out, "yesssss."

From the moment we brought him home, Debbie had Cody glued by her side. There would be no sleeping in the laundry room in a box for this big guy. Deb brought the box into our bedroom and put it on her side of the bed within arm's reach. My only saving grace was it was a Saturday night, because I just knew we would be up all night with a very whiny puppy. After an hour or more of exactly that, Deb got up and came back with some warm milk. Putting Cody and the bowl on a towel on the bed, it took Deb some coaching at first, but Cody finished every drop of the milk, licking the dish clean. With his little belly looking as if it would explode, Deb started to cradle Cody in her arms on the towel now draped across her. An hour later, Cody was still in Deb's arms and both were fast asleep.

For weeks to come, that became the nightly routine, only with puppy biscuits thrown in. Watching Cody wolf those down, I teased Deb she would turn Cody into a "biscuit-butt." Deb roared and for the rest of his life, "biscuit-butt" would become my nickname for Cody. As Deb was not leaving the house much in those days with no chemo and only taking the little magic chemo pill, they became inseparable. Even when we did leave the house when we took the long drive down to the clinic that was conducting the trial for the chemo pill, Cody being home alone was all Deb was focused on. She mothered over him to the point of almost smothering him. But then, Cody loved every minute of it.

Befitting his puppy size, Cody grew like the proverbial weed. My dad would comment that even with all the puppies he and my mom had raised, those were the biggest paws he had ever seen on a German shepherd puppy. Our dear friend Linda was stunned when she and her little black miniature poodle, Heidi, paid a visit the middle of November. Cody was already almost three times the size of Heidi. His ears were huge and they proudly stood up, bending slightly inward and touching each other over the middle of his head, making for an adorable sight. Watching Cody and Heidi sitting in the same lawn chair together was priceless. It was proverbial love at first sight.

Cody exhibited all the early signs of great intelligence. But with those smarts also came stubbornness. Like Deb, Cody knew what he wanted and he wanted it. Deb spoiling him rotten was not helping. Over my entire life and together with Deb, we would never allow any of our furry family members to be up on the bed. But all that went out the window with Cody. Deb's early nightly bedroom routine, well, became routine even as Cody quickly grew. Gradually over the months, each evening after getting his "lovin'" from Deb, he would curl up at the bottom of the bed by Deb's feet. That was at first difficult for me to accept, especially in our fancy, motorized, vibrating, queen-size bed that allowed Deb to raise or lower the head or foot area. But over the months, watching the sheer comfort and joy Cody was bringing Deb, I did not even try to fight the feeling. I gladly had a little less room on my side of the bed.

For all his smarts, his bullheadedness was clearly on display during the first round of puppy training that Cody failed. At home, he was a champ, easily and consistently not only completing the puppy exercises, but also allowing me to take him further into more advanced techniques. I was totally amazed, thinking I had another superstar like Mich. Perhaps Cody would even go beyond Mich's training, and I did not think that was possible. But once at school training with all the other puppies, all Cody cared about was playing with his fellow classmates. He wanted what he wanted and that was that.

After Cody failed his second puppy training attempt worse than the first, my hopes of another trained superstar were dashed. The K-9 sheriff who moonlighted running the training approached me after the class. After I put Cody through all the paces that he just failed in the group setting and even more, the sheriff said flatly he had not seen a Shepherd that large at his age. Given his size, intelligence, and stubbornness, we made a big mistake taking him from the litter so early.

"Cody did not get a chance to become better socialized or get his butt kicked a time or two in the litter."

But I did not want to hear what he blurted out next, nor did I believe him. "If I were you, what I would do is take him down to the sheriff's office and donate him. With full-time and much-focused training, we can work that stubbornness out of him."

He concluded with, "He'll make a great police officer, but he will never make a good family dog."

When I went home and told Deb that her boy failed again, and what the sheriff had said, she went ballistic. "What the hell does he know? He just wants to get his hands on my Cody-bear. That is not going to fucking happen!"

I was not happy as well, nor did I believe the sheriff. Even as much as I thought I knew about training a dog, I still decided, however, to hire a private trainer to come to our home. He as well laughed at what the first trainer had shared. But he did agree with one thing. Cody was big, highly intelligent, and yes indeed stubborn and would need a lot of focused training.

But as we got into training, all things considered, Cody did extremely well through the private sessions. Deb even worked with Cody. I came home early one day and stood at the back window looking out at Deb in the back yard working with Cody and playing Frisbee. That was biscuit-butt's favorite activity of all. Not long ago, Debbie was barely able to make it out of the bed. Yet even with the HOA pain raging again, there she was, playing around in the back yard with her Cody-bear.

The rest of the Cody story is that even though he would display a stubborn, playful streak the rest of his life, he was still very well trained and overall, he was THE BEST family German shepherd I ever had. That sheriff was totally wrong in his assessment, and perhaps as Deb angrily surmised, "He just wanted to get his hands on Cody to make him a cop."

Healthcare Roulette

During the fall of 2002 and heralding the arrival of 2003, the challenge with the other healthcare battle would emerge again as well. Unlike the first place Deb was treated, we had zero insurance issues with this round of hospital stays. Everything was in network. The medical center and its hospital accepted our insurance. We were not balance-billed. When it works, it works so well. The challenge was keeping it that way. The good news was that the healthcare organization I worked for had long since grown to a point that all employees could now participate in a group plan with no exclusions. For us personally, that also became the bad news.

As always it seems when it comes to Healthcare in America, there is generally a complication. The medical center treating my wife did not accept the insurance selected by my employer. Never mind this was a company started and owned by two of the South's largest insurance companies. In order to stay where Deb was being treated without going bankrupt, I had to find a way to continue to stay on the COBRA group plan of my previous employer that was accepted at the facility, or so we were initially told.

Given Deb's condition, we thought there would be no problems in getting her the needed disability determination to extend our COBRA coverage as allowed by law. Familiar with the rules and the timing of each of the qualifying dates and processes, we applied for a Social Security Disability Determination long in advance. We also notified my previous employer's COBRA administrator. All of the initial conversations with the local Social Security Administration (SSA) field office went wonderfully. The staff was everything one could hope of our public servants—kind, courteous, and caring. But as the months dragged on, it was obvious that Deb hit a snag somewhere in the process.

The first step to surviving Healthcare in America is to understand that nothing being proposed will address the systemic problems existing throughout our non-system of care and make it any more affordable or equally accessible. If middle-class America is to survive, we must understand our non-healthcare system, not the spin around it. That is the only way to increase your odds at the table.

A great labyrinth of complexity and confusion has sprung up and is standing in the middle of those trying to access care. Roadblock after roadblock is put in front of Americans by those who greatly benefit from the very confusion they have created. Our doctors and nurses are spending almost as much time accounting for care as delivering it. Instead of treating patients, they find themselves treating paper, and yet somehow more patients every day.

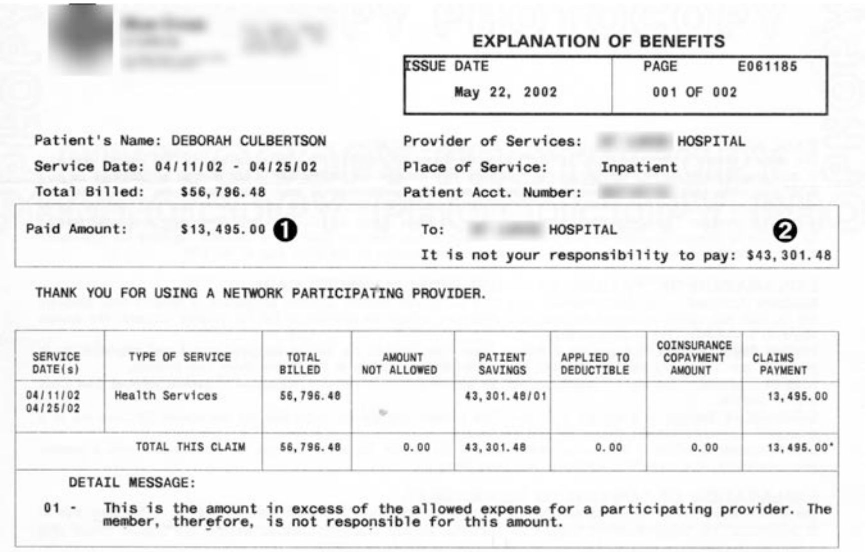
Even with all my years of industry experience, I painfully learned the hard way the time to plan for a healthcare emergency in not when the ambulance is screaming down the highway at seventy-five miles an hour. Given the way our healthcare system works, it takes planning and forethought to increase your odds against financial ruin. It will take an understanding and management of every aspect of your care to increase your odds for the best outcome. Even still, I sadly admit through our experiences and those of friends and family, even with a healthcare education—even with all the things you can do to increase your odds—it still takes one hell of a lot of LUCK.

That is my most haunting understanding of trying to survive Healthcare in America. The propaganda surrounding current efforts to deal with the crisis and give us ownership of our healthcare admittedly makes good sound bites. However, the "real bite" will come when you, your spouse, or family member is diagnosed with a disease and labeled for life, when that Health Savings Account (HSA) you thought was a great tax shelter flies out of the bank faster than you can ever put the money in—if you are one of the unlucky Americans.

Feel pain in your side? Have a headache that just won't go away? Taking one or more of those latest and greatest medications? Step right up and take the great American gamble—"Healthcare Roulette." If you are one of the lucky ones, the stars will align. Whom do you work for? How much money do you have in the bank or not? Did you magically end up in or out of network? Did the trip to your primary doctor turn into a nightmare of more doctors, more tests, and more labels?

Maybe this time you don't get caught in the spiraling and complex maze of inconsistent delivery, outcomes, and costs. Your procedure goes completely as expected. You did not have to get a second mortgage or cash in your children's college fund. Step up to the table again and the next time you may end up misdiagnosed and maltreated, with a bill that will take you the rest of your life to pay off. When a one-week planned hospital stay with a five percent chance of anything going wrong turns into a three-month nightmare. A journey filled with blood infections, more surgeries—and yes—needless pain and suffering. When you find out that the hospital front door and all the walls around you as you walked in are in the network of your insurance company, but all the doctors and the staff providing services within those four walls are out of network.

What's the difference? Well, let's take a closer look at just one of our hundreds of "Explanation of Benefits (EOB)" as an example. And a-one-and-a-two and it goes like this: After years of being on a medication to help you deal with your cancer pain, you also end up dealing with one of those little side effects. Your colon stops working and two-thirds of it must be removed. The hospital (or likely the surgery group) determines that the "list" price for the surgery is $56,796.48.



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EXPLANATION OF BENEFITS

ISSUE DATE	PAGE E061185
May 22, 2002	001 OF 002

Patient's Name: DEBORAH CULBERTSON

Service Date: 04/11/02 - 04/25/02

Total Billed: $56,796.48

Provider of Services: [redacted] HOSPITAL

Place of Service: Inpatient

Patient Acct. Number: [redacted]

Paid Amount: $13,495.00 ❶

To: [redacted] HOSPITAL ❷

It is not your responsibility to pay: $43,301.48

THANK YOU FOR USING A NETWORK PARTICIPATING PROVIDER.

SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
04/11/02 04/25/02	Health Services	56,796.48		43,301.48/01			13,495.00
	TOTAL THIS CLAIM	56,796.48	0.00	43,301.48	0.00	0.00	13,495.00*

DETAIL MESSAGE:

01 - This is the amount in excess of the allowed expense for a participating provider. The member, therefore, is not responsible for this amount.

***Learning Opportunity**: ❶ The processed claim for Deb's miracle colon surgery. ❷ At this spin of the healthcare roulette wheel, everything worked perfectly for us.*

Now the human reality is that no price tag can be put on the surgery. It is as priceless as the miracle that was performed. You are mended in a way that you wear no device and otherwise lead a normal life. Nonetheless, the financial reality is a bill that is still a hefty sum for almost any American.

If, as was our case at the time, the hospital (and staff) declares itself under contract and in the network of your insurance company, and the procedure performed was covered under your benefit plan, then things work as you would expect. All you pay is a deductible or co-pay or some other "out-of-pocket" expense. At this spin of the wheel, you owe nothing. In exchange for the opportunity to be in the health plan's network, however, the hospital no longer gets to bill $56,796.48. They must take what the health plan deems is "reasonable and customary." In this case, the new bill is $13,495. On the roll of the dice this time, you get a wonderful EOB. But its craps for the hospital, which now must take a 74.5% reduction or $42,301.48 off their price tag.

Step up to the table again and as we would a year later with the same hospital and the same insurance company and things work differently. The hospital is still in network. But the staff working in the hospital is no longer in network as a "participating" provider. More often than not, most Americans fall into this trap because they simply can't get an appointment or surgery scheduled at a facility that accepts their insurance, or some of the doctors working inside the hospital are "contractors" that do not work with your insurance company and you are not notified of this or even have a say about it. The in-network hospital is filled to capacity so you are "diverted" en route to another facility. You arrive at the hospital "out of network." This can be a devastating financial diagnosis. But most Americans fall into this trap simply because they are totally unprepared where to go or what hospitals are in network <u>before</u> the ambulance pulls them up out front.

Why? Most insurance companies offering health plans that allow you to seek care out of network charge you a coinsurance amount that is generally twenty to forty percent of what they feel is "reasonable and customary." This is the amount insurance companies believe a provider should charge. Not only do you have to pay this percentage, however, you will also likely be balance-billed for the amount above what the health plan thought was reasonable but which the medical provider did not. In this case, that difference was $42,301.48

While some states are trying to protect patients in cases where there is a true emergency and there are some instances that are tricky and not clearly defined where you will not be "balance-billed" for the excess amount, the challenge before you seek care is getting this complex understanding. This is all part of the great American healthcare roulette system. So much luck is involved.

So what could all this add up to? In this case, the $42,301.48 now marked as the "patient savings" on the EOB sample would slide over to the "Amount Not Allowed" side (patient balance) of the bill. In addition, the coinsurance and co-pay amount would change to match your out-of-network penalty. For most, this is a thirty percent coinsurance of the "reasonable" amount. In this case, that would be $13,495 times 30% or $4,048.50 now listed in the out-of-network coinsurance amount.

So, you ask again, what does all of this add up to? Simple yet horrifying math: $4,048.50 + $42,301.48. This spin of the wheel everyone wins but you. The hospital hits the jackpot. Instead of receiving just $13,495, they now get the full meter price of $56,796.48. Even the health plan wins at this roll of the dice. It only has to pay seventy percent of their reasonable and customary claims payment amount, or just $9,446.50. You are the one who goes bust at this turn on the table. You owe $46,349.98.

Claims	Total Billed	Not Allowed	Patient Savings	Copay/ Other	Claims Payment	Your Balance
❶In Network	*56,796.48*	*0.00*	*42,301.48*	*0.00*	*13,495.00*	*0.00*
❷Out of Network	*56,796.48*	*42,301.48*		*4,048.50*	*9,446.50*	*46,349.98*
❸No Insurance	*56,796.48*	*56,796.48*	*2,839.82*	*0.00*	*0.00*	*53,956.50*

***Learning Opportunity**: ❶ Claim processed in-network. ❷ How the same claim is processed if you are out of network. ❸ No Insurance? You pay the "list-price."*

For millions and millions of other Americans, the bill is not so complicated. If you arrived at the hospital with no insurance, the bill is simply $56,796.48. If you are lucky, you might get their cash discount of five percent and a cool $2,839.82 off the list price, so now you only owe $53,956.66. Until the passage of the bankruptcy reforms in 2005, many hospitals, especially the not-for-profit and endangered species variety, would work with you. Many surgeons and other physicians would take a lesser amount in many instances as well.

However, one of the side effects from the bankruptcy reforms made it more difficult to wipe the slate clean of debilitating medical debt. From dealing with billing services and collection agencies, it was readily apparent that the old adage "something is better than nothing" helped coerce more cooperation than community goodwill. The bankruptcy option was a wall that kept those at bay who would otherwise be tempted to push unreasonable payment and recovery demands. With nothing less than their survival at stake, I sadly predict that the days of goodwill and fee negotiation with the under- and uninsured are over. Squeezed from all sides, medical providers and hospitals will have little choice.

Against All Odds

As we rolled into May 2003, the magical miracle cancer pill was indeed starting to appear as just that—a miracle. Based on Deb's exams and scans in recent months, the tumor in her left lung was holding steady, but the tumor in her right lung that begat this war was starting to look as if it might have changed slightly to become just a touch smaller. Dr. Elizabeth made the determination to do more testing in July and see where we were at that point after another three months on the cancer pill.

Over the almost year on the wonder drug, Deb's appetite had fully returned and she gained back all the weight that she had lost. Once again, there wasn't a soul who could meet Deb who would've had a clue about all she had endured. The "Deb mojo" was back in full bewitching force. Despite her continuing HOA challenges, she generally felt good and was looking good! Deb was again using her oft-used refrain: "My Wonderbra ain't wondering anymore!"

Deb's chemo-free moments, taking that one little cancer pill a day along with her pain meds, were a much-needed godsend and respite. I marveled over having our Deb back again despite her battle with the HOA pain and the swelling of her toes and fingers. We even got to take Cody to experience some of his first swims in the ocean. Deb would sit in her beach chair beaming watching all those at the beach gawking at her Cody-bear. She laughed and cheered him on as he was flying up and down and back and forth on the beach and in and out of the water catching his Frisbee.

Deb even decided in the evenings to start taking short strolls out of the house with Cody and me if her HOA pain was not raging too badly. She rarely engaged in such activity during all of our years together. It was enthralling and inspiring to see this transformation in Deb. Braving her pain to go to the beach, wanting to take walks, wanting to smell the roses. She very much seemed to be taking life in more and more in that regard. She most certainly rubbed off on me.

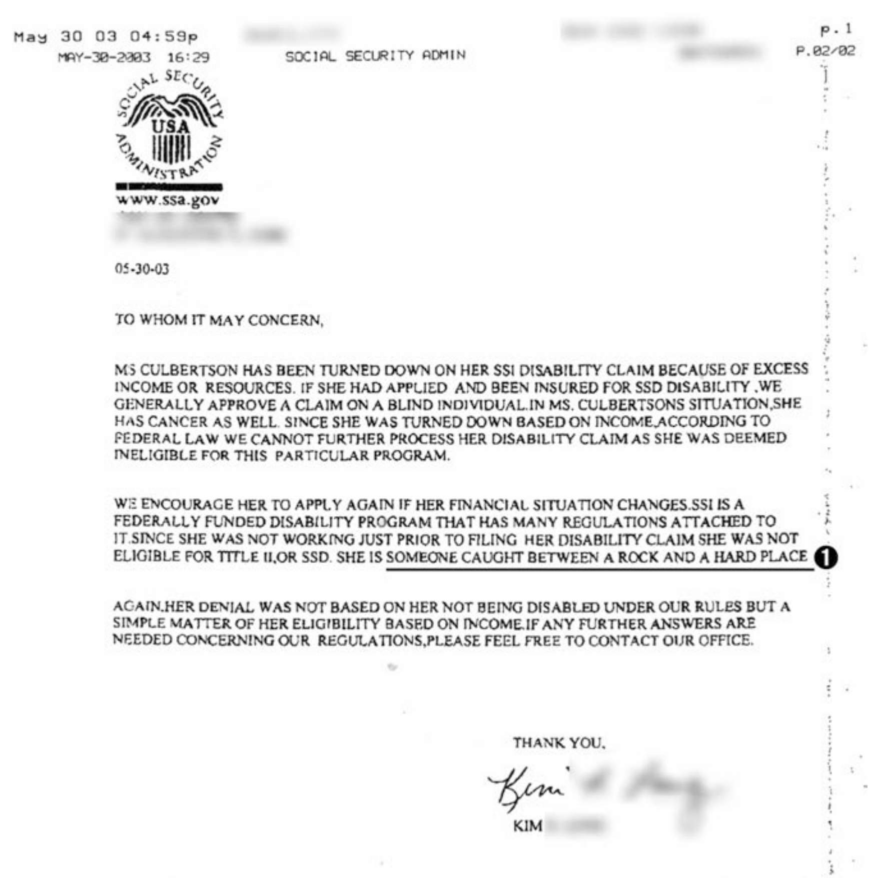
Deb even enjoyed her cancer treatment during the past year, especially cruising in our '96 Collector Edition Corvette Deb had nicknamed the "Silver Bullet," even if at times, she was challenged to get in and out of it. We always tried to make those five-plus-hour round-trip drives to where the chemo trial was being conducted special. We even took the back roads and stopped along the way for something to eat. There was one spot on a long stretch of road with lush horse farms. Several times, we pulled over just to watch the horses if they were out and running the fields.

The first time in a long time, we even got to make the trip north to visit my family. This included my dad, Walt Sr., and mom, Rita, and two of my four sisters, Brenda and Cathy, and her husband, Paul, who all lived near our parents. Our sons were extremely close to Cathy's two daughters, Lory and Lisa. Although once Deb got sick, the cousins mostly hung out long distance over the Internet. We were thankful Thomas and Steven had Lory and Lisa to confide in and share those things they could not share with us. They had the shoulders of their cousins to lean on and freely discuss their fears and concerns.

But no matter how wonderfully the care side was appearing to go with Deb being stable and not sick to death from all the chemo poisoning her body, we just could not escape that other side of healthcare, even for a moment. As we fell into June 2003, our COBRA coverage was ending. We found ourselves up against the wall, or more exactly, as officially proclaimed to us by the US government in the letter from the local Social Security

Administration (SSA) office, we were one of those Americans, "caught between a rock and a hard place."

No matter how they tried or reexamined the rules, the SSA staff could not grant Deb the disability determination. It seems that you can only get the determination if you need money from our government. Because I made too much money, we were disqualified. However, the COBRA law says you have to get a determination to be granted the extension. We were trapped in our very own circular firing squad.



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MAY-30-2003 16:29 SOCIAL SECURITY ADMIN [redacted] P.02/02

www.ssa.gov
[redacted]

05-30-03

TO WHOM IT MAY CONCERN,

MS CULBERTSON HAS BEEN TURNED DOWN ON HER SSI DISABILITY CLAIM BECAUSE OF EXCESS INCOME OR RESOURCES. IF SHE HAD APPLIED AND BEEN INSURED FOR SSD DISABILITY ,WE GENERALLY APPROVE A CLAIM ON A BLIND INDIVIDUAL.IN MS. CULBERTSONS SITUATION,SHE HAS CANCER AS WELL. SINCE SHE WAS TURNED DOWN BASED ON INCOME,ACCORDING TO FEDERAL LAW WE CANNOT FURTHER PROCESS HER DISABILITY CLAIM AS SHE WAS DEEMED INELIGIBLE FOR THIS PARTICULAR PROGRAM.

WE ENCOURAGE HER TO APPLY AGAIN IF HER FINANCIAL SITUATION CHANGES.SSI IS A FEDERALLY FUNDED DISABILITY PROGRAM THAT HAS MANY REGULATIONS ATTACHED TO IT.SINCE SHE WAS NOT WORKING JUST PRIOR TO FILING HER DISABILITY CLAIM SHE WAS NOT ELIGIBLE FOR TITLE II,OR SSD. SHE IS SOMEONE CAUGHT BETWEEN A ROCK AND A HARD PLACE ❶

AGAIN.HER DENIAL WAS NOT BASED ON HER NOT BEING DISABLED UNDER OUR RULES BUT A SIMPLE MATTER OF HER ELIGIBILITY BASED ON INCOME.IF ANY FURTHER ANSWERS ARE NEEDED CONCERNING OUR REGULATIONS,PLEASE FEEL FREE TO CONTACT OUR OFFICE.

THANK YOU,

Kim [redacted]

KIM [redacted]

Learning Opportunity: *❶ How many Americans have received a letter from their government telling them, they are, "someone caught between a rock and a hard place?" With how much luck is involved given how complex our healthcare has become, many more than you would suspect!*

The sick irony of all of this is that given the cost of COBRA coverage, not a single person in America could afford the premium if they legitimately qualified for SSA. In our case, it did not matter that we did not want money from our government, we still could not get the determination we would need. Thankfully, however, armed with that letter from a wonderful and caring person at the Social Security Administration, my kindhearted and caring former CEO, Jeff, pressed to get us the continuation on his company's COBRA even without the official SSA determination.

To this day, I have no idea what Deb and I would've done or how much more we would have paid without Jeff and what he did for us in the middle of so many other responsibilities as the CEO of a major company. While indeed at times in our healthcare journey, we lived as the unfortunate, we were among the fortunate to have those that touched our life, like Jeff.

The premiums, however, would jump to over $1500 per month. Being able to keep my wife with the doctor she trusted while "in network" was worth every penny. However, over the months that followed, it would seem we outfoxed ourselves trying to stay on top. Even with the knowledge of the system, the ability and willingness to change jobs and move multiple times, pay over $18,000 a year for health insurance, it would still not be enough to keep from getting caught up in our complex and fickle non-system.

We had what we thought was good coverage. It would seem, however, using it would be the continuing challenge, no matter how much we were paying for it. Starting from that point and until we finally got off of COBRA, we would have nothing but problems. Month in and month out, the coverage would be terminated at the beginning of each month, only to be tortuously reinstated by the end of the month. Every month the time-consuming flurry of calls would yield the same results. Not only did the health plan always confirm they had our payment, but we stayed a month ahead of each deadly premium due date.

We never did get a straight answer. The healthcare technologist and payer claims system expert in me, however, has a strong suspicion. Somewhere along the way, there was a miscommunication and glitch in one or more of the computer systems of the COBRA administrator, the health plan, or their pharmacy benefit manager.

Staying on COBRA longer than eighteen months was obviously not the normal situation. So somewhere along the convoluted flow, the staff was probably overriding their system to reset a flag or coverage indicator each month.

The result of this was more than countless hours on the phone working through the maze of companies. Every month as Deb's costly pain medications needed a refill, the trip to the pharmacy would become more of a nightmare, hell for us, and for the pharmacy staff, who bent over backward to assist us.

During the year and up to summer of 2003, we continued to be blessedly fortunate to have only primarily needed that pharmacy benefit during this time. Deb continued not undergoing any treatment except pain control and that magical little pill being provided as part of the clinical trial. We marveled over the day when a simple little pill would replace the myriad of costs and deadly complications of treatments like chemo.

Now we just wanted to marvel over a functioning system. We could not get a full month supply of several of Deb's pain meds because of the rules and, combined with the refill timing of others, we would end up at the pharmacy several times a month. Every month like clockwork standing in the often-crowded pharmacy line, we would get the word:

"The computer says your insurance has been terminated or expired."

The other eyes in the line would start to roll as you were now taking up understandably precious time of the pharmacist, making their wait in line longer. As the pharmacist and everyone else in line listens in, you protest. "How can this be again?"

The knowledge we are paying an exorbitant amount each month, always well in advance, did little to diminish the embarrassment and did nothing to ease the shame on the way out, as those eyes in line stared down what they thought was just another deadbeat wasting their time.

The pharmacist had few answers and only one option. Do you want to pay cash and the list price or not? As with the medical side of things, when the insurance does not kick in, you are not asked to kick in what insurance would have paid. You pay the full "retail" price.

Many times, as Deb needed it, we had no choice. While the pharmacist states you can always get your money back, my observation and our real-world experience were that that rarely happened. Even when the pharmacy handled the process, which they sometimes did, all it seems you are reimbursed even after filing the forms was what the insurance "would have paid" at their discount price, not the retail price you paid.

As the summer months wore on, one of the pharmacists would even start to jockey for the position not to be the unlucky one to assist us. We were grateful for our two pharmacist angels, Moria and John, at the pharmacy we most often tried to use. Even still, it easily took fifteen or more minutes each time to go through the drill that always seemed to produce the same result: "Sorry. Your coverage has expired. Cash, charge, or do we put it back on the shelf?"

It would not be until well into the fall of 2003 that the glitch was finally resolved and the pharmacy started to not be such a hassle. Under the category when it rains, it pours, the clinical trial Deb was on for the wonder cancer drug was ending. We were initially concerned that the "free" clinical trial office visits that were being billed to our insurance at a rate of $350 per office visit would not be covered by our insurance and that the medication would be priced so high, if covered at all, that we would not be able to afford it.

But it was not just the cost of the office visit or the drug that was concerning us, it was the periodic and superficial ten-to-fifteen-minute interviews that $350 paid for. It was easy to see how drugs have problems that do not get documented in the trial and only come to light long after the drugs are released. Even though Deb was in the clinical trial for over a year, no one ever contacted her or followed up on her outcome. It did not appear there was much of a connection or coordination between Deb's oncologist and her treating facility with the facility executing the clinical trial.

But even still, in Deb's case, the outcome from that little miracle pill was nothing short of just that—a miracle! It was clear the tumors were not growing and Deb's cancer remained stable, and a once-a-day pill that we hoped could more comfortably control Deb's cancer was having some wonderful results replacing chemo.

Nonetheless, we were stunned when our fears were realized as we received the news that the medication, once approved and on the market, was minimally going to cost over $2,000 per month. Deb was horrified it could take many months if ever before the insurance company would add the newly approved drug to its formulary. While drug companies sometimes offer a break on new drugs, that break is "means-tested," which meant that as with the SSA challenges, we would be forced to pay out of pocket each month for the drug on top of our COBRA premium. When combined with our insurance payment of over $1,500 and other out-of-pocket costs, we would be staring down almost $4,000 a month.

However, given the list price of weekly chemo sessions at over $7,000 per week, versus the list price of $2,000 per month for this wonder drug, there is indeed a hopeful glimpse of the future. Compared to the debilitating impact of chemo, such drugs will still prove to be the easiest $2,000 a month that could ever be spent. That is unless, of course, you do not have $2,000 a month of disposable income to afford it.

But even the magic of that wonder drug did nothing for Deb's old nemesis that chemo had once controlled, but which had now again taken complete control of her life. No drug the rheumatologist had tried was working on the HOA. At this point, it was totally out of control. Deb could barely stand or walk around. Her hands, feet, and ankles were severely swollen. She could hardly move her knees or get out of bed. Her sometimes nighty walks and trips to the beach were devastatingly over.

Three months since Deb's last CT scan and visit with Dr. Elizabeth, Deb approached her July 2003 appointments hoping the changes that were seen in her right lung would be even more pronounced and that the tumor in her left lung, if not shrinking, at least stayed the same. But as we once again sat across from our venerable and beloved Dr. Elizabeth, we would receive neither of those desirable results.

The CT scan yielded what appeared to be no changes in the right lung that had been treated since Deb's battle started. But the originally misdiagnosed tumor in the left lung, which was held in check for the year by the wonder drug, now was starting to grow and with it, the enzyme believed to cause the HOA. This explained why in recent weeks Deb had been in more pain and discomfort. Deb's most recent trip to the chemo trial even had to be made in our SUV because of the difficulty getting Deb in and out of our Corvette.

A year after having my first talk with my sons, I feared I would be doing so again. I had hoped that with the help of Deb's closest friend, Linda, Deb would start to, in earnest, write those letters to her sons as Dr. Todd, our pain management savior, had once suggested. He had shared with us during one of our visits, one of the most touching ways that Deb could reach out to her children after she was gone. Upon graduation from medical school, to his surprise, Dr. Todd was handed a letter from his father, who had passed away before he could see his son on that stage. He urged Deb to do the same for her sons, even as difficult as they would be to compose.

Linda had offered to help Deb in this most monumentally difficult task. She was one of our dearest and most respected friends and trusted angels to assist Deb. Before Deb was sick, we had lived in the same town as Linda. I was consulting to a local health plan and teaching at one of our state universities located in town. As always, one of the reasons Deb and I picked the neighborhood we did was so our sons could go to one of the best elementary schools in the area. Linda was a teacher extraordinaire there, as well as the school's technology coordinator.

The Internet and leveraging websites were still a budding idea in the late nineties and early 2000s. Noticing that our sons' school did not yet have a website, I came up with another of my volunteer schemes, helping the boys' school create their first-generation online presence. So vivid is the day that I first met Linda in the library of the school as we sat down at one of the tables to talk about my ideas. Linda was everything and beyond you would hope of a teacher. She was not just caring, kind, and thoughtful, she was highly intelligent, intuitive, and resourceful.

Linda patiently heard me out, and to my thankful surprise, she enthusiastically supported the opportunity for her school. A website would be a new communications resource for teachers, students, and parents. We sat at the table for several hours that afternoon and brainstormed a whole new way to share information for the school and individual teachers. I learned so much that day and in the weeks to come as we worked together. I clearly saw how much Linda gave of herself to help her students, especially given the lack of school funding and resources for even the basics, much less a technology endeavor such as a school website. She was motivated to volunteer to do whatever was needed for her school and its students.

Over the months of working together, Deb and Linda became close and fast friends and we started to socialize. After many years of Deb not having a close friend other than her sisters, it was heartwarming to see Deb get so close to Linda. Now in for the fight of her life, it would prove to be fortuitous timing that Deb developed such a deep and caring friend. Linda was such an inspiration. She motivated me to want to help others. With Linda's help, I propagated what we were doing at her school to other schools in the area. Before I knew it, I was volunteering for five different schools.

Meanwhile, our other angel would again shower us with her determination at life. After reflecting weeks on our situation and Deb's now-worsening condition, the third week of July 2003, Dr. Elizabeth decided to order another PET test to verify the results of the recent CT scan and order another CT with different contrast. She was determined to see if the cancer was spreading and causing Deb to now be almost HOA bedridden.

No Hope to Hope in Less Than a Minute

As soon as Dr. Elizabeth came into the exam room, she had one of the happiest and pleased looks I had seen on her face in all the years we had come to know her. In the space of a few minutes, we again went from no hope, trying to resign our little family and ourselves to our own mortality, to again being blessed by how quickly <u>miracles</u> can happen. While the tumor in Deb's left lung was indeed growing, the miracle was that was the <u>only place</u> the PET had detected any trace of cancer.

What the redo of the CT with contrast was showing in the originally diagnosed right lung was now scar tissue from the radiation but no visible uptake of her cancer. Over time, Dr. Elizabeth had seen a marked reduction in cancer in that lung. It would seem that some combination of original radiation Deb received along with "real" chemo and the miracle cancer pill did the job we never thought could be done. With her beautifully warm and wide, toothy smile, Dr. Elizabeth pronounced, “Looks like you are operable, Deb. Let’s get you quickly set up with the surgeon, and see what he thinks this time.”

In less than a minute, Deb went from being non-operable and terminal, to operable, and with all the hope in the world that she could now be cancer-free after the surgery. Mere days later, even given her great pain on the day of the surgery consultation, Deb jumped out of bed as much as she could. There we were again meeting with the best of the best who we had spoken with several years before.

Only this time there was something the surgeon could do. He carefully explained that he expected the procedure, called a lung resection, to go very well. In fact, he called it “routine.” He even estimated there was only a five percent chance of anything going wrong, and Deb would only be hospitalized for about a week.

“This is a very routine procedure I have performed many times,” he reassured us.

As before, the surgeon also had another interest besides Deb’s surgery. He was documenting Deb’s case for the medical books. The surgeon was intrigued by her HOA from the moment he had seen Deb two years before. Looking at her now, he was even more stunned at how the HOA had raged in the year that she had been off chemo.

He promised Deb, “You will feel immediate relief from that HOA, from the moment you awake from surgery.”

They did not understand all the details or how it worked, he explained, but in other cases, they had documented this fact. As Deb was filmed before, she consented again to be closely monitored and filmed before and after the surgery.

Next, we would hear a catch. The surgeon was going on vacation. He discussed the options including whether to get someone else, do the surgery before he left, or postpone it for a month. Seeking his advice, he suggested that given the routine nature of the procedure and that Deb would be in great hands until his return, he felt “very comfortable” doing the procedure before he left. Given the experience of the colon surgery and how little interaction we had with the surgeon once the procedure was completed, Debbie decided on the spot she did not want to wait another month.

"Oh no, we are not gonna wait. I want to get this thing out of me, now!"

The surgery was set for one week later, the beginning of August 2003. As many times before on this meandering journey leading into a war, Deb and I found ourselves sitting at the traffic light waiting to exit the medical center staring at each other. This time in divinely stunned disbelief as overwhelming waves of happiness and thankfulness washed over us. The silence in the car was only broken by the thunder of our kiss. We kissed and kissed and kissed until finally, the car behind us blasted their horn.

Deb endured almost three years of hell and back. She was often given little hope, little time with too many interceding conversations with our sons. They tragically lived their mom's up-and-down struggles, including those recently, right alongside Deb and me. In seemingly the blink of her beautiful blue eyes, I found myself sitting next to Superwoman. She continued to defy all odds and do battle with all foes. Once again, ostensibly pushed to the edge of the cliff, only to have a miracle reach out from above and snatch her back.

Deb could barely get through the door as she excitedly hugged and kissed her Cody-bear and had him dancing all about her even though he knew not why. She shouted to the boys, who emerged not knowing what to make of the scene in the living room unfolding before them at first. "See I told you! Your old mom ain't going ANYWHERE!"

Pointing to her right side, she said, "The cancer in this lung is long gone," and then over to her left, added, "and this one the doctors are going to operate on next week and take out of your mom! I ain't going to be sick ANYMORE!"

HOA pain be damned, the week that followed was wondrous as we spread the word high and low among our families, friends, my co-workers, and industry workgroup colleagues. They had been empathetically following Deb's journey as I often used what was happening in my personal life as ammunition for all we were trying to accomplish within those healthcare transformation efforts.

The night before her surgery, neither Deb nor I could sleep. We lay in bed mostly silent, lost in a million thoughts, fears, and hopes, all choreographed by the background noise of the TV. Deb periodically jostled a snoring Cody, worn out from my extra-long pondering walks, from his affirmed spot at the bottom of the bed by her feet. She jokingly admonished him, "Damn, Cody-bear, you snore louder than your dad over there!"

Of course, that always led to the inevitable bed debate over who snored most out of the three of us. But my most engrained memory of that evening was an overwhelming sense of what I can only describe all these years later as, "hopeful fear." While on one hand great optimism, yes, but on the other, we had already developed an uneasiness with the hospital and all the things that can befall you there. But we consoled ourselves that this was a much easier procedure than before, in appearance.

This was, after all, "a one-week planned surgery and hospital stay with only a 'five-percent' chance of anything going wrong."

After the surgery, while Deb had great pain from the procedure, as promised she did feel immediate relief from her HOA pain. Just as forecasted, as soon as she awoke from surgery, the ends of her fingers and her toes no longer stung as if she had just walked into the warmth after being outside in the snow. Deb could finally move her legs and within days, her ankles started returning to normal size. Over the weeks following surgery, her fingers and toes, which had looked like mini-lollipops before surgery, returned to normal size. Her fingernails grew straight, no longer curved or hunched over.

But that night, lying in her hospital bed, Deb would again be confronted by the inability to obtain good pain relief. It seemed the experiences of before would be lost on the pain management staff. The tolerance Deb had built up over the years of intermittently being on the maximum dose of strong pain medication was not well understood. As with all of her previous hospital stays, Deb was again placed on far too low of a dose of pain medication to start with. She begged to see the pain management doctor on duty. The nurses continually apologized and said they were trying.

Hours and hours passed and nothing happened except for the pain getting worse. Finally, late into the evening and not knowing what else to do, I finally reached for my cell phone and the number of Dr. Todd, our pain management angel who had once worked there. We were not at all surprised when Dr. Todd left as the best of the best, to make a difference in rural Mississippi. There are some angels. Connecting through his beeper system, within no time, Dr. Todd called me back.

"How's it going, Walt? How is Debbie?"

He was surprised, thrilled, and yet also dismayed at what I was telling him. He told me to tell Deb help was on the way. In the middle of the night, a miracle from so far away, Dr. Todd reached out and tagged his former colleagues.

Not more than an hour after our phone call, another wonderful doctor appeared in Deb's room.

"Good evening, folks. I am so very sorry it took me so long to get here! It has been one of those kinds of nights. I can look at your face and see the pain," she shared as she walked over and took Deb's hand.

She continued to apologize profusely for not making it sooner as she quickly started to work. She had more than her hands full as the only pain management specialist on duty in that entire facility with floor after floor of patients. In the middle of babies being delivered—emergency surgeries rolling in the E/R door—and patients scattered about the facility, she took the time. She made the difference.

Over the next half hour, she personally administered medications that immediately brought relief. She talked to us about her colleague, Dr. Todd. We were all obviously proud and honored to say we knew him. Not just anyone would leave a medical center to go help the underserved in rural Mississippi. I shared how grateful I was that Dr. Todd helped me get HIPAA on the agenda at a pain management conference. The doctor looked at me with a teased fake glare.

"Oh, so you're one of them, hey!" Then, laughing, she said about Dr. Todd and HIPAA, "It takes a lot of guts to add real pain to a pain management conference."

She also talked to us about what we were already starting to see. Dwindling staff and cuts in the face of an always booked and crammed facility. The difference in care and attention to detail was obvious as nurses and doctors are pushed to the brink each and every day.

After the surgery, it was immediately apparent that Deb had a complication known as a pneumothorax. The lung had a leak and would not inflate. We were told this was normal and that was why she still had a large chest tube in her that was routinely put into place during the surgery. While most often the tube is quickly removed, this would not be one of those times.

Over the next few days, the pain would be a challenge but at least under control. I finally went home for a night. I will selfishly say a dad could never ask for two braver or finer sons. How over the years Thomas and Steven have dealt with the trauma and the turmoil, fear, and pain seeing their mom hooked up to all those machines and knowing they could lose her at any time.

We were so fortunate for the help of my good friend Mr. Bill. Many times, so many times, he stopped by to check on our boys and deliver them a meal or take them out. Even still, they spent many of those evenings left alone. All the while, their mom was in the hospital fighting for her life. Thomas and Steven never broke down or lost their focus on their schoolwork and routine. They have much of their mother in them, of that, there is little doubt.

The next day after checking in with the office and going over to the facility, I was mad at myself for leaving Deb. Throughout the night even as she kept pressing the PCA button, the pain relief that she was getting when I left was no longer working. Instead of the medication running out several times through the night as normal, by the next morning, Deb hardly made a dent in the bag. Deb tried all night long to get someone to do something, but those assigned to her room only saw what appeared to be a working PCA.

Fortunately, when her oncologist, Dr. Elizabeth, arrived as she so often did to check on Deb, she would quickly get to the source of the problem. The last nurse to change the PCA had done so incorrectly and reprogrammed it. Almost no mediation was being delivered with each push of the button. It was of little comfort at the time that at least the nurse had not spun the pendulum in the other direction.

Over the course of the days that followed and the rest of her time until discharge, Deb remained as comfortable as could be, considering the lung resection and a rib that was surgically broken and partially removed. The greatest pain, however, was from the chest tube that was still inside her. With no sign that the air leak was going to close, it was decided as Deb was already in the facility for now over a week, that Deb would be released with the chest tube in her to finish recovering at home under the care of a visiting in-home nurse.

From the first in-home nurse visit, I did not like the look of the chest tube site. Over the next few days, Nurse Ann, who we were so fortunate to get assigned to Deb's homecare, started to agree. Also, however, both the surgical site and the needle site where Deb had an IV in her hand also started to look infected.

Every day Ann took Deb's temperature and checked her other vitals but Deb did not have a fever. Her hand looked so bad that I started to treat it with triple antibiotic cream. Ann agreed with my decision and every day called in the results including her observations of the site. Every day the infection got worse, yet Deb did not develop a temperature. I had to start changing the chest tube dressing several times a day because it became so soaked. When Deb coughed, fluid would literally stream out of her.

A few days after Deb was home, I did not think the chest tube was working and shared my observations with Nurse Ann. Deb's pain was much worse. She felt like she had a great pressure built up inside her chest. She had increased difficulty breathing. More drainage was flowing around the chest tube and out the now-widening wound rather than being caught in the chest tube fluid bag. Ann jumped on the phone and was insistent with whomever she was talking to on the other end of the line.

"The patient has to be seen, temperature or not!"

Are You Breathing?

Later that morning, I was in my home office just about to start an important long-distance conference call with my boss, Julie when Ann knocked on my office door. She said she had gotten them to agree to see Deb and that I should take her immediately.

Having already missed so much work from the week before and given the importance of the call, I tried to juggle one ball too many that day. Going down the highway sixty-five miles an hour in the center lane talking on the cell phone to those on the conference line, I looked over and Deb was slumped down with her chin on her chest.

To the horror of everyone on the phone, most especially my boss, Julie, in an instant, the call shifted from legal and other discussions regarding preparedness for upcoming HIPAA compliance dates. They now heard me asking my wife several times, "Are you OK? Hey, Baby—are you still breathing?" Then a quick, "I'm sorry, but I have got to drop off the call."

I pulled over to the side of the road on the highway as quickly as I could and with my own heart jumping out of my chest, shook Deb several times, each time harder as Deb gasped and her eyes opened and closed.

"Are you OK, Baby? Are you OK?"

That was such a stupid question. "Something is seriously wrong," Deb weakly shared. "I just feel like I can't stay awake. I am so dizzy and my chest is so heavy. I'm having a hard time breathing. I'm scared, Baby. Something is not right in there."

The rest of that nightmare of a trip was a blur until we got to the hospital. When we got there, the surgical staff took us in right away. Sara, the young doctor who was the surgeon's assistant (resident) met us in the room. Dr. Sara did not seem at all interested that my wife had just passed out. We tried expressing our concerns about Deb's worsening condition and what we were seeing at the chest tube site in her side as well as her hand. The doctor, for the most part, ignored our concerns and seemed focused mostly on Deb's temperature.

She told us in her best assertive voice, "not to worry. The amount of drainage will subside. Once I unclog the chest tube and it is working properly, you'll breathe easier."

Sure enough—Deb immediately felt relief and could breathe easier. I carefully studied everything the doctor had just performed. But Deb was still in severe pain at this point. Unfortunately, it appeared that the chest tube was in to stay at least until her next appointment. Given her understandable discomfort, Deb was prescribed another narcotic in addition to those she was already taking.

As I had expected, Julie was indeed greatly alarmed when I jumped off our call earlier. After I got Deb home, she was my first phone call. I could clearly hear on the other end of the phone how shaken Julie was. Unsurprisingly given her great caring nature, Julie expressed not only her great concern but offered me, as she always did, great flexibility to work from home or wherever I had to work, or even not, to be able to take care of Deb. We were again so blessed she was in our corner.

Days later, as it would often turn out, I would come to be so glad that I studied so closely all that was going on with Deb. In this case, the chest tube procedure that she had. A few nights after rushing Deb to the hospital, she woke me in the middle of the night. She had great difficulty breathing and her chest was tight. I looked and sure enough, the value connected to the tube connected to a drainage bottle appeared to be blocked again. I debated what to do—911 or play doctor. But I quickly received my marching orders.

"Just fix the damn thing," Deb commanded. "Just do what you have to do, damn it, and DO IT NOW! I can't breathe! I can't breathe; you gotta do it."

I performed the procedure exactly as Dr. Sara had. It quickly worked like a charm. Deb was able to almost immediately start breathing normally as the great pressure in her chest subsided. Nurse Ann, our home health nurse, checked my handiwork the next morning with a smile as we compared notes on the procedure.

Over the days to come, however, Deb just got worse. Her hand and back started oozing in addition to what was coming out of the chest tube. The surgical scar extended from the top side of her rib cage around and almost midway to her back. The chest tube was just below that. Each morning Nurse Ann would change all the dressings. She started also using a bandage on Deb's hand with a stronger prescription antibiotic cream to replace the over-the-counter (OTC) cream I had been using.

In the evenings, I repeated Nurse Ann's procedures. We would again get disappointing news at Deb's follow-up. There was no change in the pneumothorax. Now a little more than two weeks after her surgery, we celebrated Deb's forty-sixth birthday. Though she was talking and certainly seemed with us even as she sang part of her own birthday song, we would find out later that Deb would have no memory, at all, of her birthday or the weeks to come. At this point, her side, back, and hand just continued to get worse.

The following week, Deb had another surgical consult. But the drive over was starting to remind me of the last. Deb was very pale and was not communicating well. She struggled to keep her head up. She had great difficulty sharing what was happening within her.

"Baby, I am so tired! My lung just does not feel solid. Not like my other lung. It is so hard to describe. It just does not feel right when I breathe. Breathing makes me so tired."

Once in the waiting room, Deb just did not look well at all. She was even paler and her lips started to develop a bluish tint. I knew straight away that the tube was blocked again. Even though I had already checked in, I went back to the desk.

"My wife is not doing well. I think her chest tube is blocked again," I exclaimed, at this point in I am certain a wrought and panicked voice. "We need to get someone to see my wife, like NOW."

The nurse looked up and over at Deb slumped in the waiting room chair. She quickly concurred. Before Deb could even see the surgical resident, the staff brought out a wheelchair and whisked Deb away. Around and around the hallways we went. Deb finally arrived at the E/R side of the house. We were fortunate that day. Another angel entered Deb's life. Instead of Deb seeing resident Dr. Sara, we got one of the other head surgeons, Dr. Sandy. He listened to Deb's lung, looked at the chest tube and her back and confirmed that the leak was still there. He cleaned out the tube again and Deb was able to breathe easier and her color slowly returned.

After reading Deb's notes, he stated with a disappointing look, "Your lung appears not to have made any progress at all in the weeks since surgery!"

Dr. Sandy was equally concerned about Deb's worsening condition and decided they needed to take a closer look at what was happening in her lung, around the chest tube site, and her hand. He told Deb that it would take a day or two to schedule the procedure to better examine the original surgery site. In the meantime, he offered to admit Deb right away. But he felt it was her decision. Given the choice, there was none for Deb. She decided, of course, to go home and wait it out.

"Hell yeah," she hoarsely said on the way home. "There is no damn way I'm staying in that place if I don't have to."

With as serious a look as I had seen from Deb and at this point with tears streaming from her eyes, she added, "I'd rather wait it out or die at home!"

But Deb did not wait long for the next bout with the hospital. The rest of that day and into the next, Deb continued her spiral downhill. Deb felt something had changed in her lung for the worse. The infections in the original surgery location and her back, hand, and the site of the chest tube continued to ooze more and more and more. Less than two days since we met Dr. Sandy and her last trip to the E/R, Deb was back again. This time Deb was immediately admitted. Within days of being in a room on the general care floor, she was transferred to ICU.

At this point, it was "officially" determined that Deb did indeed have a raging infection. She would be in ICU for over three weeks fighting for her life. It would take the extraordinary care of the new surgeon, Dr. Sandy, and that of an infectious disease specialist. It would also take weeks of trial and error and ultimately the most powerful antibiotics available to turn the tide on the infection.

During the fight for survival, one morning the staff came into Deb's room and placed big yellow signs around, including a large warning on the front of her ICU door. The infectious disease physician sat me down and told me that in all probability, during the surgery, Deb was given a serious yet common infection called Methicillin-Resistant Staphylococcus Aureus or more commonly and simply know as MRSA.

She warned me to "take great care around your wife! Make certain anyone visiting your wife's room understands that they must be highly cautious. Everyone must scrub their hands and always wear gloves. They must also wash their hands after removing the gloves when leaving the room."

Then she gave me the orders that so pained me as I looked over at Deb as she blankly stared at me. "Do not kiss her and again be careful around your wife and only touch her with gloves on. No skin-to-skin contact."

Over the days since Deb was transferred to the ICU, her breathing became shallower and her pulse weaker. I started spending countless days and nights not sleeping and staying with Deb around the clock, except for quick late afternoon trips home to shower, change clothes, and check on Thomas and Steven as they arrived home from school and make certain their dinner was squared away or that my friend Mr. Bill would be over later to help.

As with our dearest friend Linda, I do not know what Deb and I would have done without the help of my good friend Mr. Bill, as I always referred to him and expected our sons to as well. During the many nights I spent at the hospital with Deb, knowing that Mr. Bill was there in our corner was a godsend. Even after working long days in the very demanding and high-stress business of computer consulting, Bill never hesitated to do all that he could. When I did not see him, we spent time just talking on the phone, especially when I was at the hospital. Bill would always make certain the boys were covered, including taking them out for meals or bringing them food and hanging with them and trying to help them in any way that he could.

Over the weekend, Deb's mom, Jeanne, and stepdad, Ken, arrived in town. When they walked into the ICU, to say they were stunned at the turn of events since the surgery was an extreme understatement. Looking at me, then over at their daughter, they saw two human messes. There was the one lying in the bed and there was the one standing in front of them.

After Jeanne and Ken spent some time at Deb's bedside and not wanting to try to wake her up, they commanded that I go down to the cafeteria and get some coffee and something to eat and take a break. I should not have been so easily persuaded. When we arrived back at Deb's ICU room, there were so many doctors and nurses in Deb's room, I could not make my way over to Deb's bedside as our horrified parents stood in the hallway looking on.

The doctors were just bringing Deb around after having given her the drug Narcan that she had to be given many years before when we first learned of Deb's severe allergy to morphine. This time it was given to combat the now-month on a complex mixture of other pain meds. The head ICU physician told me they had no other choice but to try to deal quickly with a rapidly deteriorating situation. In response to the Narcan, Deb may have developed ventricular tachycardia and hemodynamic instability. We almost lost Deb to save her.

Deb would later describe all of the things we have read about regarding near-death experiences. Flashing lights, hearing voices down below, most of all a loud humming noise and feeling an electric shock like no other when she was given the "anti-drug" drug. While Deb would again have great pain-control issues as everything in her system was effectively canceled out, her vitals improved dramatically. In the middle of the night, however, Deb would start to slip again.

Over the next few days waiting for Deb to recover, I became concerned that she had not had anything to eat since coming into the ICU. How did they expect her to get better if Deb was only getting liquids and no nourishment? None of the doctors in the ICU seemed to share nor wanted to focus on that concern given so many other serious issues.

I was never so glad to see anyone as the kind and caring infectious disease doctor who turned Deb's care around making her rounds. As she listened to me, we added up the days since Deb's last real nourishment. She gave me the good news that she strongly concurred that we needed to immediately "feed her." But then she shared the bad news. Because of the blood infection, they could not give it to Deb intravenously. It had to be through a tube in her nose and down her throat. I am still haunted by that day. So vivid, my memory of standing outside Deb's ICU room after the team forced me to leave my wife while they did what they "needed to." I stood there in the hallway listening to great pain and discomfort as the tube was inserted, hoping that I had done the right thing in pushing the issue.

Over the next week, Deb slowly recovered as the infection was finally brought under control and Deb was ultimately able to sit up to eat so the tube could be pulled. Our family, who had started assembling days before not knowing the future, could now relinquish the ICU waiting room that we had effectively taken over for almost a week. We listened, stunned and dismayed, as Deb not only started to come around but also a collective realization as we talked to Deb that she could not remember anything since just after the surgery except the moment that did stick with her: when she saw the flashing lights and heard the loud buzzing sounds. She could not even recall her own birthday party weeks before.

At this point, the original surgeon finally returned from his vacation. We were surprised when he and the surgery resident, Dr. Sara, walked into ICU unannounced. To say that he was stunned to see his patient like this was an understatement. While the good news was that he was back in town, the bad news was he was leaving again! This time he was headed to a medical conference. But the surgeon promised to see Deb over the next few days before he left. He would then catch up on everything that had transpired.

Later, seeing me exhausted and reflecting on the conversation we had earlier about sons, one of the ICU nurses came over that night and strongly suggested that I needed to go home and "spend the night with those boys." After relaying some of the episodes at the hospital and all the things that seemed to happen when I would leave, he promised Deb was in good hands. He was a former army medic and we compared notes about my days in the Navy and plans of becoming a doctor. He immediately placed my business card with my cell number in his pocket as I shook his hand. Looking me in the eyes, I could see that he clearly understood my concern and fear of leaving Deb. But I instinctively trusted him. I knew he had Deb's back.

"I will call at the first sign of anything happening with your wife. And I will make certain to keep an extra eye on her throughout the night. You have my word on that."

The next day I was so relieved that nothing happened and that Deb was scheduled to have the same ICU nurse that evening. At Deb's insistence, I decided to relent and go home again another night. I really wanted to spend some extra time with our sons and take them out to one of their favorite restaurants, then walk with them to school the next morning with our rambunctious and lonely Cody.

But upon arriving at the hospital the next morning and seeing one very distressed and weeping Deb in the bed, it smacked me straight in the face. I, again, made the way wrong decision the night before to leave her! I listened in disbelieving horror as Deb shared what had happened while I was gone.

In the early morning hours, the surgeon and his resident assistant, Dr. Sara, appeared in Deb's room. He told the nurse that he needed to clean up the site of the chest tube wound that was now gaping open from the weeks of infection. As the nurse left the room, he closed and drew the curtain around the ICU glass door as Deb looked on.

The surgeon appeared rushed. After removing the dressing, he started to explain to the resident in great medical detail what she had to do. Lying on her good side looking up at the resident, Deb clearly saw a startled and frightened face. After a few minutes of back and forth, finally, the surgeon very directly stated he did not have time for this. He had to make his flight. Telling my wife it would be like removing dead skin from a blister, he started.

With no anesthesia, it was not like a blister at all. Deb screamed, cried, and begged him to stop. But the doctor just kept doggedly cutting away the skin around the site of the chest tube where it entered her body. He cut away so much that the tube was now loose in a hole that was far greater in size than the tube. Deb started bleeding badly as the surgeon tried to put sutures in place. He could only get one. Through her tears, my wife, still looking up at the resident, watched as Dr. Sara's eyes widened. The surgeon stated that the tube was in place well enough for now, but he also explained what Dr. Sara needed to do the following morning.

Right after they left, another nurse came into the room to a patient in tears and still shaking. The doctors had not even bothered to put a dressing over the site. The nurse softly stated that they had left it for her to finish. When she heard and saw what they had done, she became as angry as my wife was hurt. Within a few feet of the table where the surgeons had just worked, the nurse opened a drawer full of anesthesia.

She walked over to Deb and took her hand in her gloved hand and said again softly, "There was no excuse for what they did to you. None. No excuse! I am so very, very sorry. So sorry."

Stunned, I just could not wrap my head around everything that Deb had just shared. Without question, I damn sure would not be going home anymore to sleep. Later that day, I made as quick of a trip home as I could to hustle together a quick meal for the boys and walk Cody, who we all felt so bad for. He was lost and confused, not knowing what to make of Deb being gone and me coming and going. After I made certain they were squared away for the night and had everything together for school in the morning, I left them again, trying as best as I could not to display my grave concern for their mom.

I sat in the chair and, like so many other nights, trying to keep one eye on Deb while clicking away on my laptop trying to keep my other eye on my other full-time job. Although admittedly that night, I found that task so much more challenging than normal. I did not even drink any coffee or leave her room for fear of leaving Deb unguarded for even a minute.

Knowing that the resident would be in early the next morning to perform the procedure the surgeon had ordered the evening before, I waited. I was determined not to close my eyes for a second.

Care in Training

In the wee hours of the next morning, I watched a new crop of residents arrive in ICU. Over so many weeks and nights, the routine and faces of this medical center teaching hospital were becoming far too familiar. It was when the shiny new face at the ICU door appeared that I instantly became worried. Most of the time the non-resident and more senior residents overlooked the rule that all family had to leave the ICU at night and each morning for several hours during the ICU shift change. Not today. Not the bright, new, young "doctor in training" standing in the door.

I tried to explain what had happened the night before and why I needed to be there when the surgery resident arrived. No matter what I said or how I said it, the young doctor was adamant and insistent that the rules were the rules, and I must leave. I continued to refuse. Sometime during the discussion, I looked over and realized that Deb was now awake and listening. As the doctor suggested she had no choice but to call security, I had my own suggestion.

"When they do come, you better tell them to bring a damn stretcher, because the only way I am leaving is if I am taking my wife with me when I go. I refuse to leave her alone!"

The doctor left. I waited. I watched the clock tick away. Past the no visitor time and well beyond. Several days later, the young foreign doctor and I would cross paths again in the hallway. As soon as she saw me coming, she went the other way. Watching her walk away, I felt bad for this new doctor who was fresh out of medical school and appeared to be new to our country from her strong accent. What a terrible welcome to American healthcare I gave her. But nothing would ever dissuade me from my mission to stand guard over Debbie, just as our German shepherds always stood guard over our family.

Not only did security not show up, neither did Dr. Sara, the surgery resident I was waiting for. As I waited for the resident, Dr. Sandy, the new surgeon who was helping with Deb's case, came into her room mid-morning. He expressed his surprise that the original surgeon was there the evening before. Even more surprised as he patiently let my wife get it all out, along with a good cry. As he passed her a tissue and helped Deb regain her composure, he maintained his thoughts about the incident, except for the fact that the surgery resident had not shown up to finish the job.

As he looked at what was done the night before, he promised that he would get to the bottom of things. He looked in her chart but found no orders documented. In my observation over the several months, this was a common occurrence. Many discussions and many decisions, yet often little documentation about either was recorded. That is why I was so determined to watch over Deb. In this case, no one would have known that Deb needed the chest tube site closed the rest of the way. Given her still-raging infection, it could have been disastrous if the wound would have remained gaping open. Within a few minutes, we could hear the resident's name being paged over the intercom. Then again. Then again.

Later, Dr. Sandy returned to say the resident must not be there that day. He had a jammed surgery schedule but he would send his physician assistant (PA) by later to finish closing the chest tube wound. We were not at all surprised, however, when later came and it was not the PA, but the surgeon himself, still in a surgical gown and in between operations, who came walking in Deb's room. Using the anesthesia in the very drawer that the nurse had shown Deb, he took his time and made the entire area numb. While the needles hurt, especially on now-very-raw areas, I watched as Deb did not shed a single tear as Dr. Sandy stitched the chest tube to her side and closed the area around the tube.

Each day thereafter, Deb got stronger and more alert. For several extra days, Deb stayed in ICU until there was space available on the critical care floor. At this point, Deb would brag to one of the nurses that she had been on almost every floor of the hospital. Over the next eight weeks, she sadly would be able to say every floor.

Through what turned out to be almost three months mostly spent in the hospital, Deb would be confronted with great inconsistency in care and pain management. Even given the huge warning signs on her door, nurses and doctors would routinely come into Deb's room without taking any time to perform the required sanitary procedures. While many took the time to wash and put on gloves, others did not. It seemed the only consistent team following the rules was the family. Many days the bedding went unchanged until we complained. Trash, paper, and soiled medical material would overflow in the trash cans in her room. We often had to hunt down our own towels and soap for the bathrooms. Even gloves when we ran out.

Without question, we met the most caring and wonderful nurses and staff, who took great care, but who were greatly overworked and overstressed by the routine and the long days. At nights as they made their rounds, they spoke of their love for nursing. That is, the way it "used to be." Now they were treating more paper than patients, but more patients than ever with an ever-shrinking team. Given Deb's personality and having survived all she already had, much less what was to come, she was a favorite of many of the nurses. Several came by even when they were off-shift and would stay and chat with Deb and me. It is clear that our system is not only failing its patients, it is also failing our doctors and nurses.

Even the unhealthy ones felt a need to talk to Deb, like the nurse who took all of her vitals, touched everything of importance including the IV equipment, coughing and complaining about the system. She bemoaned she was a nurse who was going broke paying for an older and oral form of what my wife was on for her infection. It seems that the nurse developed a lung infection the year before.

She made it sound like one of the problems of the job, like miners and black lung disease.

Yet, she barely washed her hands, sometimes did not put on a pair of gloves and never wore a mask. When completed, the nurse simply and directly marched from my wife's room past all the warning posters and across the hallway to the next patient's room. But as with so many of the hospital staff and routine, she very quickly blew in and out of our lives, never to be seen again.

One day as my mom Jeanne and I sat in the waiting room of the imaging department, we were stunned, concerned, and saddened by the conversations going on all around us. Many discussions were about infections being given to their loved ones, themselves, or friends. As it has always been obvious where her daughter got her outgoing personality, Jeanne made many friends over the weeks she ultimately would spend at the hospital with me over the years. I truly do not know what I would have done without my other mom. We clearly heard that her daughter's infection and hit-and-miss medical care and lack of sanitary care was tragically, sometimes deadly, not unique.

As dismayed as I was, I could not fathom having been Jeanne hearing all we did and seeing the results on her daughter. But then Mom was strong. I saw that from the first moment that I met Deb's parents. I was hooked. I was astounded to see how much Deb resembled her mother in appearance and grit. It was easy to see where Deb got her beauty. It was also plain to see where Deb got her great Dutch determination, strength, courage, and tenacity.

But even with great love and support between them, Deb had a complex relationship with her mother that I often could not quite figure out. Many times, after being with us for a week or more, Deb would let her mother know in her own way, she needed her space or whatever it was that Deb was going through inside at the time. Jeanne would sometimes get a not-too-subtle message from her daughter that it was time to leave again until the next visit. Jeanne was not only my rock but she was as well for so many others. I felt great pain for Jeanne as so many friends of hers and Ken over the years also battled cancer and often leaned on Jeanne for help, wisdom, and strength.

In the six weeks that had elapsed since the surgery, the lung leak simply would not close. Finally, it was decided that Deb would undergo a scoping procedure to see if the air leak could be viewed and possibly fixed. Sometimes it was possible, we would be told, to place a staple into the area to close the lung using an attachment on the scope. As Deb had TMJ surgery many years before, even before getting sick, she always wore a bracelet that warned of the forced opening of her jaw. Debbie was terrified that they would have to go down her throat again.

When Deb finally was whisked away and the medical team performed the scoping, Dr. Sandy and the other doctor who performed the procedure made Deb as comfortable as possible. Later, the performing physician came in to explain the results, which did not go as they had hoped. He then tried to describe the surgical procedure Deb would now have to undergo. But the entire time, I watched as Deb's face turned red and her eyes watered when she saw Dr. Sara, the surgical resident whom we had not seen now in many days, was with him. As the doctor tried to explain the results, the resident simply would not stay in the background this time, trying, I suppose, to display that even after she did not show up before, she was still the doctor.

Unfortunately, the real doctor who had actually helped perform the scoping procedure and whom we wanted to hear from could not get a word in edgewise. He gave up and suggested he would see Deb again later. The doctor returned to the room early evening at the end of a long day for all. He apologized about the events earlier and, without directly criticizing his colleague, made light that new doctors can get anxious. He carefully explained that as best as they could understand what happened in the original surgery, the flap that was created during the resection procedure did not close, or it reopened.

At that, Debbie laid it on him. "I want that Dr. Sara removed from my case."

He suggested, "Well, I am not the person to talk to about that."

He politely yet quickly exited once the conversation shifted from the results of the scoping and the new planned surgery that would be needed to close the open flap.

The next day both the original surgeon, and the resident, Dr. Sara, showed up in Deb's room. Deb said little. She later shared she did not want to make an emotional scene in front of them or appear that something other than logic and reason was guiding her decisions. Later, when Dr. Sandy, the new surgeon, came into Deb's room to see if she understood everything they learned from the scoping, Debbie told him directly and calmly, "I have lost all confidence in my surgeon. I never had any in Dr. Sara. I want both of them off my case!"

Dr. Sandy said that he was more than willing to address the surgery part, but even as her new surgeon, it would seem he did not have the power to remove the resident. Only the teaching team had that power. Later Deb spoke with the three young residents who were the teaching team assigned to her case when she was moved onto the floor. We would find out that it seemed no one had the power. Despite my wife's strong protest and determination, the resident remained on her case. Dr. Sara did, however, maintain a very low profile from that day forward.

The next morning the original surgeon appeared in Debbie's room. He said that he had a talk with his colleague whom my wife wanted to do the procedure. Making small talk to the effect that too many cooks spoil the soup, he let her know that Dr. Sandy would be completely taking over her case. He apologized that things had gone so wrong, that Deb always seemed to be on the wrong end of the five percent chance of something going wrong. No less included was her getting an infection—all the things you are warned about, which sound like they are too remote to happen, until they do.

"To YOU!"

From Routine to Challenge

The first surgery was described as routine. This surgery would not be routine. It would involve a plastic surgeon in addition to the surgeon. Each would perform a portion of the overall complex operation. In order to repair and close the lung, a rib would have to be removed. A large piece of muscle would also be moved from Deb's back and placed into position in the lung to help form a wall that would keep the lung closed and in place so that it would not collapse again.

As Dr. Sandy would later say, “We could have left the chest tube in place forever and that leak would never have closed on its own.”

What made his comment even more horrific and painful, weeks before, Deb had begged and pleaded with the ICU doctors to surgically close the leak! Now here I was with our mom, Jeanne, and dad, Ken, nervously pacing back and forth in the surgical waiting room once more. My mind in so many places, lost in the many weeks that had transpired and all that my dear wife had endured. Thinking about our sons, all the time they had been left alone, and so very thankful for friends like Mr. Bill, and physicians like Dr. Sandy.

After a successful surgery and now in recovery, the first words Deb would say to me, even before she could fully focus her eyes, were loud and while pained, clear.

“It feels solid this time. My lung feels solid when I breathe.”

Over the next week, we would see that even being in the Primary Care Unit or PCU, one step in between the intensive care unit (ICU) and the regular hospital floors, would not resolve the same issues of consistency of care and lack of support for the infectious disease control program. While the care was more critical in PCU, we did not notice any increase in staff or resources. Jeanne would, in fact, proclaim her daughter had received far better care “on the fourth floor” in a “regular” room.

Some other highlights included having the suction pumps connected to the now-two large chest tubes coming out of Deb turned off. It took over five hours of waiting and watching Deb again in agony before the approval came to turn them back on. Several times the pain management doctor on duty would visit and make adjustments or additions to her pain medication. Even when it was recorded in her chart, however, the nurses never seemed to get the news quickly or otherwise put in motion the orders. Sometimes hours would lapse before the new medications were made available.

Much of this was not always neglect. It was overwork. Again, we met so many wonderful, caring, and troubled nurses along the way. We can never forget Nurse Brenda, who came in on her day off to check on my wife. Two days before, things were looking good for a Monday discharge, but it all hinged on her pain control. We were fortunate to finally get a pain management doctor on duty the end of that week that finally turned the pain around for my wife. On that Friday, he crafted a precise weekend game plan to slowly get her off of the IVs and onto oral pain medications for a planned Monday discharge.

First thing on Saturday morning, however, the pain management doctor on weekend duty listened to no one but his own brilliance. Talking down to everyone in the room, he immediately ordered oral medication and the pain IV pumps shut off. Nurse Brenda, who had been there the day before and heard the original game plan, protested in vain. The doctor blew her off just as easily as he did my wife. The pills he ordered could not get into Deb's system or have the strength to work quickly enough. He sent Deb on a quick downward spiral. By the end of the day, Deb was beside herself in pain again.

Nurse Brenda, who witnessed the events of the day, came by at the end of her shift. She said that she had spoken to the other nurses coming on duty and as soon as that doctor was off shift, they would get the next pain management doctor involved. Sure enough, in no time the doctor on duty came by. As he listened, he said little about the events of the day. While he was honoring the other code that some doctors seem to have, <u>tell no harm on another doctor,</u> the look on his face said it all as he immediately changed the orders. He also authorized the nurses to inject pain medication throughout the night as well.

The next day, early Sunday afternoon, Nurse Brenda, who saved Deb the day before, walked into her room. In her civilian clothes, Nurse Brenda washed her hands, put on a set of gloves, and sat by Deb's bedside talking to us for hours. But what astounded us and restored our faith the most was when she shared why she was there.

"I came back to make certain that the weekend day doctor did not go back and overrule the doctor from the night before."

The one time we did not wish to see a pain management doctor walk in the room, we would most fortunately get our wish. That other doctor never came back. The orders remained.

As we sat that afternoon, Nurse Brenda shared her time in healthcare and how wonderful yet difficult it was to be a nurse. Much to the detriment of patients, and her fellow nurses, she lamented how much things had changed over the years since she graduated from nursing school with great pride and optimism for her career of caring for others. How much more they were now expected to do each day on longer shifts with less staff and fewer resources, yet more patients. I opened up and shared my own stories and why I went into the Navy with dreams of becoming, of all things, a maxillofacial oral surgeon. This, after the things I witnessed as an Army brat growing up during the Vietnam War.

I shared as well why I ultimately did not become the physician I had always envisioned from childhood. The more the nurse and I chatted and considering all the things I had learned, the more I could clearly see how fortunate I was to have had my Navy experiences and the responsibility of patient care before I spent years going to both medical and dental school. But then in college, I found my first love, computers and programming. I was blessed to have been exposed to "data processing" going to college at night and exited stage left out the healthcare technology door after my Navy tour of duty.

We talked about family members who were in the "business." I shared how proud yet so very concerned I was for another Nurse Brenda, my sister, and my niece Karen who is a nuclear medicine specialist. My courageous sister Brenda went back to nursing school later in life and started a whole new career. She uses her great caring and love for others in the hospice wing of a nursing home caring for those who truly need the most care. My sister is amazingly special and her patients truly blessed to have Brenda as their beloved guardian nurse.

Many hours after she first arrived, that beautiful, caring, and kind angel of a nurse left knowing that all would be quiet that afternoon as no drug changes would occur. I will never forget her. I will never forget her kindness and care. I will never forget her heart. Nurse Brenda was a very special person and nurse who despite all odds and obstacles thrown in front of her, was focused on one thing above all else and one thing only—her patients. She represents her profession with the utmost integrity and dignity.

But the weekend pain setback cost Deb, our wallet, and the system three extra days before she was discharged. The middle of the first week of October 2003, eight weeks after that first five-percent-chance-of-anything-going-wrong lung surgery, Deb was finally wheeled through the hospital doors and discharged once again. We requested Nurse Ann, the same wonderful home health nurse from the agency we had before. In addition to all her other chores, Nurse Ann also would now have to spend several hours a day while she ran the antibiotic IV that Deb still required to finish her battle with MRSA and her infectious disease treatment.

Things were finally looking up. The left lung felt solid. The infection was starting to get under control. We followed a precise routine. We had to clean the new and original surgery sites on her side and back and the chest tube site with peroxide-soaked Q-tips three times daily. These were placed deep inside the incision that had opened up from the infection. As when I was in the Navy, it was difficult for me to cause another painful discomfort, but with Deb's distressed encouragement, I persevered. Over those weeks, Deb's hand was finally clearing up. But the site of the original chest tube was very slow and painful to heal. But the process started and Deb was at home.

Despite all she just endured, and still groggy from her pain and the pain medications, it was clear Deb's impenetrable spirit to persevere remained untarnished. She insisted on making her way each day into the front room to sit upon her cherished throne. Deb loved her recliner rocker. Centrally positioned, Deb could survey much of the comings and goings on the first floor. She loved gazing out of the tall wall of windows to her left, where she could spend hours peering out to a picturesque backyard on the edge of a tree-lined conservation area.

Over the next days, Nurse Ann arrived each morning and delivered Deb's antibiotic IV and checked her healing wounds while they chatted away. They shared coffee and conversation. Nurse Ann represented all the reasons I thought I wanted to be a doctor in the first place so many years before. With her wonderful care, we went into the weekend thinking everything was finally on the rebound. We could not begin to contemplate, given everything that had gone wrong, what else possibly could?

Back to the Battle Again

But just a few days later on a once-calm Saturday night, around 2 a.m., I woke up to the sound of Deb again in unbearable pain. Unable to breathe, she gasped, "I can't believe this is happening again, Goddammit. My lung collapsed again."

Gasping for air, she wheezed, "I'm telling you, Baby, my lung has collapsed again. I can't breathe. I can't..."

But, shockingly, I quickly realized Deb this time was holding her right side, not her left where she was just operated on, and my heart started pounding harder and harder.

"Baby, what lung collapsed?"

Deb could only get her words out in between each difficult breath. "It feels like my whole damn chest has collapsed. But it is hurting on the other side too, and bad—very bad."

I could see the fear in her eyes. I immediately dialed 911.

"I need an ambulance here now! My wife just had major lung surgery and she cannot breathe. She can't breathe, please come NOW."

Many kind words have been shared in recent years about our other saviors in blue. I will again add to the chorus of Americans who will forever be thankful for the skill, care, and sacrifice of our fire and rescue services. On many occasions in the middle of the night or the middle of the day, they arrived and each time transported Deb quickly to the hospital facility. After the episode on the highway when I had to drop off a phone call trying to get Deb to the hospital, I learned then to never attempt to be the ambulance again.

It was with great anguish that I once again had to wake our sons up in the middle the night and tell them what was happening.

"The EMTs will be here shortly to take your mom back to the hospital. She is having a little hard time breathing and I'm going to be leaving with them and follow the ambulance to the hospital."

I was crushed and demoralized, looking at their young, once-again terrified faces. "Everything will be OK and you dudes know what you need to do. Make sure you let Cody out in the morning and feed him before you get yourselves off to school. Hopefully, we will be back here before you guys get home from school."

As was typical every time they came, the EMTs had great difficulty getting Deb out of our bedroom because of an alcove entrance. With the boys watching and trying to keep Cody at bay until I ordered him to his place, the EMTs very carefully got Deb into the stretcher and tried the best they could, sitting Deb up, which was very painful for her, to maneuver her out of our bedroom door.

The boys came over to their mom and Deb took the oxygen mask off and told them she would be, "OK." Even in as much pain as she was in, the last thing she had to do before she was taken out the door was to see her boys and her Cody-bear. I released him from his place, making the paramedics more than a little nervous. But they quickly saw all Cody cared about was Deb on that stretcher. She rubbed his head as he licked her face and the oxygen mask.

Once again, I found myself trailing behind the flashing lights of the ambulance, which freely made its way to the hospital emergency room, given the lack of traffic at that time of the morning.

At one point, I had pretty much run a red light trying to keep behind the ambulance. A squad car came out of nowhere from one of the shopping centers and quickly pulled behind me and stayed on my rear bumper. I can only assume after the officer noticed as we all made the exit onto the highway and my trailing so closely behind the ambulance that I was following it. I was extremely fortunate that instead of pulling me over, the officer took the next off-ramp and got off the highway.

Once at the hospital I quickly pulled into one of the emergency spots and was able to walk up to Deb as they were taking her out the back of the ambulance. Many of the E/R team recognized Deb as her stretcher was wheeled inside. Several commented they could not believe she was back. No one was in more disbelief of course than my wife, especially as Deb heard the news that the months of stress on the left lung likely stressed an already-weakened right lung, causing it to collapse. The admitting process started all over again while they prepared to put in yet another chest tube. This time it was for the other lung.

The emergency room staff worked hard that night to make Deb as comfortable as possible before and during the chest tube insertion and getting Deb readmitted once again to the hospital she had developed a great fear of. I could not imagine what Deb had been thinking passing through the emergency entrance once again.

At this point tragically predictable, the awesome care in the E/R would not continue once she got to the floor again. The big snag this time would be that they could not find the medication orders from the E/R, including the list where the EMT crew had dutifully documented what she was already taking. Never mind the fact this was where she was just discharged from who had put her on all those medications! That list included the antibiotic Deb could not miss a dose of under “any circumstances,” we were told. But because of a shortage, they did not know when, or if, the hospital would be able to quickly obtain enough of the drug, especially given the inevitable weekend challenges of obtaining care or medications. Despite the rules against using meds from home, I left Deb, rushed outside and jumped on the road. I wished all the way home and back that I had that ambulance in front of me again.

As it would turn out, the facility did indeed end up using the antibiotic I brought from home because they could not find any on the floor that weekend. I also had to bring our own supply of smaller 3/4-inch port needles the home health nurse Ann had been using at our home. The hospital stocked nothing but the standard longer port needle. Those caused delivery complications, however, as my wife’s port was much closer to the surface than most. So much for that hard-and-fast hospital rule that you are never to use your own medications or supplies when you are in a hospital facility.

But all day long, Deb continued to suffer from her other nemesis, trying to obtain pain relief. Finally, toward evening, they got her pain under control. The chest tube pump whirling away, Deb could see, I suppose, that I was anxious. The other side of healthcare was looming. My day job! Deb knew I had a critically important meeting the next day. She ordered me home to be with the boys, especially considering how she disappeared from them in the middle of the night before.

“Get your ass home and be with those boys. Take care of what you need to. I am fine and you can see that for now, I’ll stay that way.”

Deb did look better. She even joked, "This time it was just a little old collapsed lung." I left, but with great trepidation.

She was right, however, about our sons needing me. I arrived home to a Thomas and Steven who were themselves anxious about the events of the night before. Their mom was once again being taken away by an ambulance in the middle of the night. Once again, they had gotten home from school and she had not returned home. During that night, neither Cody nor I could sleep. I finally got up early in the early morning and took Cody for a long walk. After I got the boys off to school, I went to the hospital first, made certain Deb was OK, knowing that I would be dragging ass that day and through my important meetings. I was trying once again to juggle so many balls, but none more important than Deb.

Yet, more so than ever these days, there were so many parallels to my day job. Everything Deb and we as a family were living made me more determined than ever that the healthcare company I worked for achieve the initial HIPAA regulatory compliance deadline of October 16, 2003, for the HIPAA electronic transaction standards and medical codes. Someone had to start laying the asphalt for the health-e-highway, making it easier for doctors to get paid and check patient benefits, and securely share our health records with each other and patients. We needed to get the word out to "*we*" the patients about our ability to obtain and control our personal health information.

But once again, as with so many times before, I would come to regret leaving Deb, regardless of my lofty healthcare goals or Deb's orders. When I arrived at the hospital, that parallel became *The Twilight Zone*. When I walked into Deb's room, they were just wheeling in a portable X-ray machine. Deb could not breathe. She could not move. As I helped the technician sit her up to put the plate behind her, Deb said over four hours before, she had felt her lung collapse. Over those hours since she first pressed the nurses' button, they forced Deb to have respiratory therapy, blood gases, but mostly they just waited for the surgical doctor-on-call to contact them. But the doctor never did.

At the nurses' station again, ready to jump up on the desk, I saw Dr. Sandy's physician assistant (PA) coming down the hall. He saw me and immediately went to Deb's room. He took one look at her, checked the chest tube that had been put in over the weekend, and instantaneously cleared the room and ordered a chest tube kit. Just then, to our surprise, the original surgeon sprinted into the room and confirmed the collapsed lung.

Even though he knew how Deb felt about the past, he still came to Deb in her time of need and immediately took charge. We were so very thankful that he did. Looking on, he carefully advised the PA exactly where to place the emergency chest tube as he recalled her case and the radiation scarring in the top of the right lung. With a new chest tube in place, the lung immediately inflated and the pressure and pain eased and Deb could fully breathe again. When the PA started to remove the non-functioning chest tube, the original surgeon ordered him to leave it in place and consult Dr. Sandy first.

Both Deb and I thanked the doctor as he waited in the room for quite a while to make certain the new chest tube was correctly functioning. He wished Deb the best and departed, leaving Deb and me feeling a little conflicted about our harsh feelings toward him. We were thankful that he was in the right place, at the right time, this time.

Throughout the day, we demanded to know what had transpired. Why I, the patient's husband, had to be the one to initiate care? Again, the nice person from the office of administration came by. Again, she scribbled down everything we said, including that during this stay, when Deb arrived, she was not given an allergy band to wear. Earlier that morning another new doctor was trying to help with the pain and started asking why they were not using morphine.

I was far worse than dismayed and exceedingly disappointed once again in myself to have only noticed, AT THAT MOMENT, that Deb was not given that familiar orange allergy bracelet when admitted this time. I ripped myself apart inside and out over my mistake. My god, I was with Deb over those days and I never once noticed she did not have that critical orange bracelet on her wrist.

"How could I have missed that?"

But more, "HOW COULD HER MEDICAL TEAM?"

Again, we would never hear nor see any results from administration. Later that morning, Dr. Sandy solemnly arrived in Deb's room. He deeply apologized but then shockingly shared what he had found out of the events the night before.

"Somehow, the beeper for the on-call surgeon had malfunctioned."

As Dr. Sandy removed the non-functioning chest tube left in Deb that morning, he had few suggestions except the next time he would unquestionably and directly be contacted!

Can’t Be Happening Again

Dial 911

I often think of that October day in 2003, when Deb lay in a hospital bed for half the night with a collapsed lung. Later, after the flurry of doctors and nurses would leave us once again staring at each other, Deb asked me a simple question in her pain and through her now tears and fear.

“What do I do if that ever happens again?”

The only thing I could think of was to tell Deb, “Never allow the phone to leave your side. If it does, then in any way you can, reach for it or demand that the nurse put it in your hand.”

Drawing close to Deb, now eye to eye, it just came out. “Then with everything you have left in you, Baby, I mean everything, you DIAL 911! Dial 911 and then if you can, dial my ass!”

Over the week, the doctors waited once again for another lung to close the leak on its own. During this time, we would again ride the up-and-down roller coaster of inconsistent care, pain management, and cleanliness. By Friday, it was apparent that Deb’s lung was going to go the way of her other lung and was simply not going to close on its own. As we learned, this time her collapsed lung (pneumothorax), was most probably due to the radiation scarring from the treatments at the beginning of Deb’s battle. We wondered aloud whether Dr. Polaroid, Deb’s first radiologist, and his old radiation equipment, was at the root of this current medical meltdown.

For hours, I again found myself pacing in the surgical waiting room. Pacing from one side of the room to the other, then from the front to the back and around each chair, I am certain I must have been driving everyone else in the surgical waiting room crazy. So many times and so many hours were spent in that room. I just couldn't make sense of everything that was happening and where Deb was once again. Hoping never again, yet I could not help wonder how quickly I would once again be pacing this room at another surgery. I was despondent.

Before Deb would experience another healthcare miracle, we would again be reminded of the reality of its meltdowns. After so many procedures over so many months, we finally watched as Deb was finally given a Betadine bath before her surgery. Deb said that was the first time in all of her surgeries that pre-procedure was performed on her.

"Well, that sure as fuck is one hell of a day late and a dollar short," Deb bemoaned after the Betadine bath.

It was so tragically heartbreaking, yet as well symbolic, that Deb and I were having that conversation on the eve of another surgical procedure. All the scars on her body laid bare not just the havoc that MRSA wreaked on her body, but a scarring chest tube hole site was now a crater in her side and was difficult to look upon. But how, how did a one-week planned hospital stay and surgery with a five-percent chance of anything going wrong, go so terribly wrong? While almost three months on the calendar, we lived an eternity each and every one of those days.

But that night, as tragically as Deb's tortured care seemed to spiral, the phone call that came next sent us spiraling down the other side of our healthcare nightmare. That night of what we had hoped against hope would be Deb's last lung procedure, we received a frantic message from our son Thomas. The patient accounting office of the facility was trying to reach me on an "urgent matter" was the message they left with him. Of course, with his mom in the hospital, my son thought something was wrong with his mother. I nervously called the next day hoping that no financial snafu was brewing that would complicate Deb's surgery. On the phone staring at my wife once again in the hospital bed, my turn finally came on the accounting department's phone line.

I would hear the good news. We owed no balance at the hospital because it billed under one name and the insurance paid "in network." However, the medical center where Dr. Elizabeth worked and where my wife had been receiving care for almost four years, and who completely staffs and runs the hospital, bills for the medical staff under a different name and was NO LONGER in network.

As the claims for Deb's three-month stay were just starting to hit our mail, as that is how long it takes to get medical bills in America, for the first time, we started noticing problems with the billing between the facility and the insurance company. We painfully started to realize that the benefits and marvels of trusting all Deb's care to a single facility could literally and overnight turn into a huge financial nightmare.

The next day, in the time it took to have a two-minute conversation with the customer service representative of the insurance company, we went from owing nothing to owing everything. Over two and a half years at the same facility with the same insurance carrier, with the same policy, the customer service representative was directly and matter-of-factly telling me on the other end of the phone, "I'm sorry, sir, but that provider group is no longer in our network. They must have dropped out the beginning of the year."

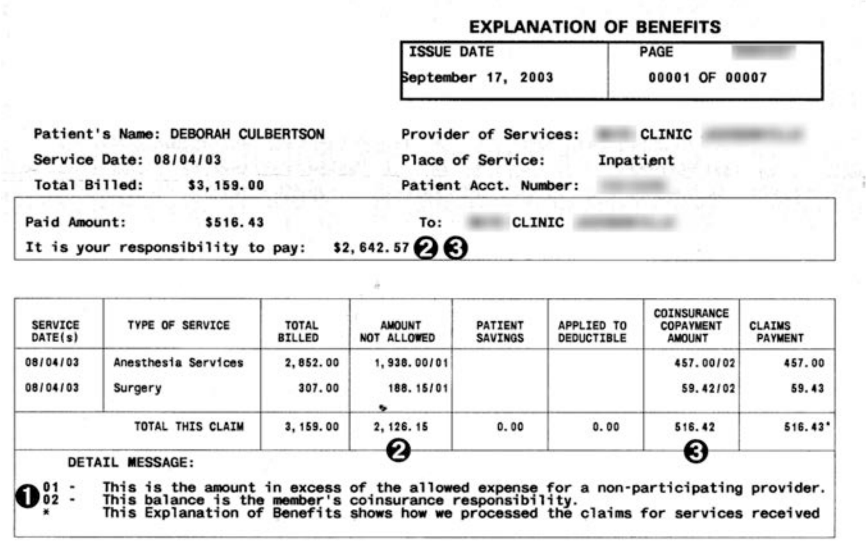
When I asked her if I should have been notified, I received nothing but silence on the other end of the phone. After a long pause, the customer service agent concluded our discussion with her own inquiry.

"Is there anything else I can assist you with today, sir?"

During Deb's first two years, we had no issues at either the facility or their hospital. Because she was on the cancer pill, we had few visits up to this point in 2003. But just when we needed it the most, however, that would inexplicability change. We had no changes in either our insurance or the facility; just changes in the determination between those companies on how they would play in the healthcare sandbox with each other at this spin of the healthcare roulette wheel.

"OR NOT!"

The result was we would no longer pay just our high deductible and co-pay as we had done in years past. Now we would be forced to pay thirty percent of what the insurance deemed as reasonable and customary and then one hundred percent of everything above. The insurance had authorized every single procedure as "in network" before any treatment was performed, yet as the bills rolled in, we would be judged "kind of sorta" in and out of network. Deb would call it, "death by a thousand claims."



EXPLANATION OF BENEFITS

ISSUE DATE	PAGE [redacted]
September 17, 2003	00001 OF 00007

Patient's Name: DEBORAH CULBERTSON
Service Date: 08/04/03
Total Billed: $3,159.00
Provider of Services: [redacted] CLINIC [redacted]
Place of Service: Inpatient
Patient Acct. Number: [redacted]

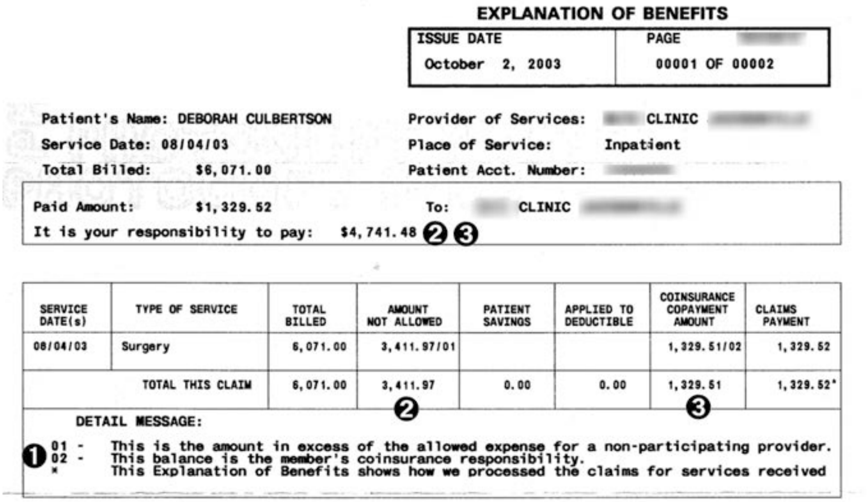
Paid Amount: $516.43 To: [redacted] CLINIC [redacted]
It is your responsibility to pay: $2,642.57 ❷❸

SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
08/04/03	Anesthesia Services	2,852.00	1,938.00/01			457.00/02	457.00
08/04/03	Surgery	307.00	188.15/01			59.42/02	59.43
	TOTAL THIS CLAIM	3,159.00	2,126.15 ❷	0.00	0.00	516.42 ❸	516.43*

DETAIL MESSAGE:

❶ 01 - This is the amount in excess of the allowed expense for a non-participating provider.
02 - This balance is the member's coinsurance responsibility.
* This Explanation of Benefits shows how we processed the claims for services received

***Learning Opportunity**: ❶ Is your doctor suddenly non-participating (out of network)? ❷ Then you pay what the insurance did not. ❸ Plus your coinsurance.*



EXPLANATION OF BENEFITS

ISSUE DATE	PAGE [redacted]
October 2, 2003	00001 OF 00002

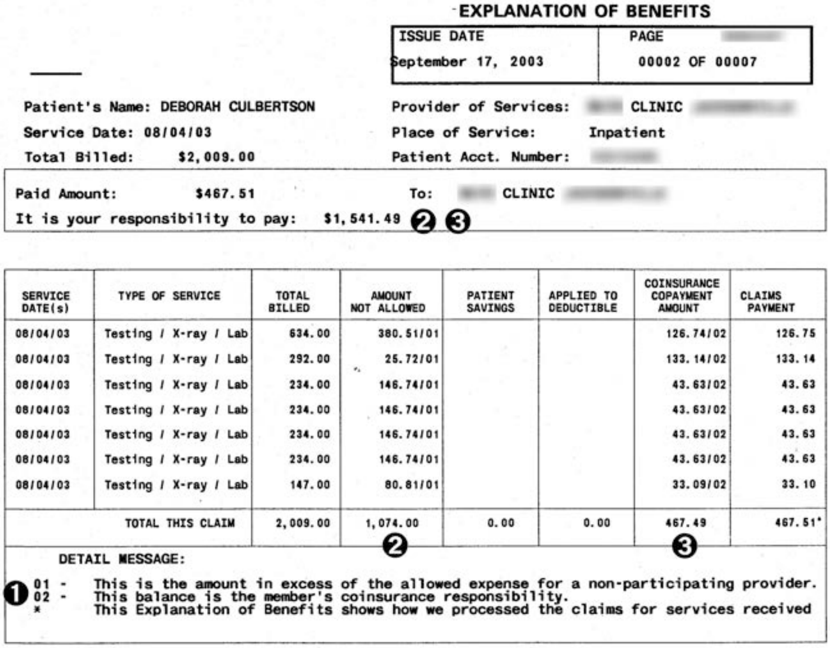
Patient's Name: DEBORAH CULBERTSON
Service Date: 08/04/03
Total Billed: $6,071.00
Provider of Services: [redacted] CLINIC [redacted]
Place of Service: Inpatient
Patient Acct. Number: [redacted]

Paid Amount: $1,329.52 To: [redacted] CLINIC [redacted]
It is your responsibility to pay: $4,741.48 ❷❸

SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
08/04/03	Surgery	6,071.00	3,411.97/01			1,329.51/02	1,329.52
	TOTAL THIS CLAIM	6,071.00	3,411.97 ❷	0.00	0.00	1,329.51 ❸	1,329.52*

DETAIL MESSAGE:

❶ 01 - This is the amount in excess of the allowed expense for a non-participating provider.
02 - This balance is the member's coinsurance responsibility.
* This Explanation of Benefits shows how we processed the claims for services received



EXPLANATION OF BENEFITS

ISSUE DATE	PAGE [redacted]
September 17, 2003	00002 OF 00007

Patient's Name: DEBORAH CULBERTSON
Service Date: 08/04/03
Total Billed: $2,009.00

Provider of Services: [redacted] CLINIC [redacted]
Place of Service: Inpatient
Patient Acct. Number: [redacted]

Paid Amount: $467.51 To: [redacted] CLINIC [redacted]
It is your responsibility to pay: $1,541.49 ❷ ❸

SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
08/04/03	Testing / X-ray / Lab	634.00	380.51/01			126.74/02	126.75
08/04/03	Testing / X-ray / Lab	292.00	25.72/01			133.14/02	133.14
08/04/03	Testing / X-ray / Lab	234.00	146.74/01			43.63/02	43.63
08/04/03	Testing / X-ray / Lab	234.00	146.74/01			43.63/02	43.63
08/04/03	Testing / X-ray / Lab	234.00	146.74/01			43.63/02	43.63
08/04/03	Testing / X-ray / Lab	234.00	146.74/01			43.63/02	43.63
08/04/03	Testing / X-ray / Lab	147.00	80.81/01			33.09/02	33.10
	TOTAL THIS CLAIM	2,009.00	1,074.00 ❷	0.00	0.00	467.49 ❸	467.51*

DETAIL MESSAGE:

❶ 01 - This is the amount in excess of the allowed expense for a non-participating provider.
02 - This balance is the member's coinsurance responsibility.
* This Explanation of Benefits shows how we processed the claims for services received

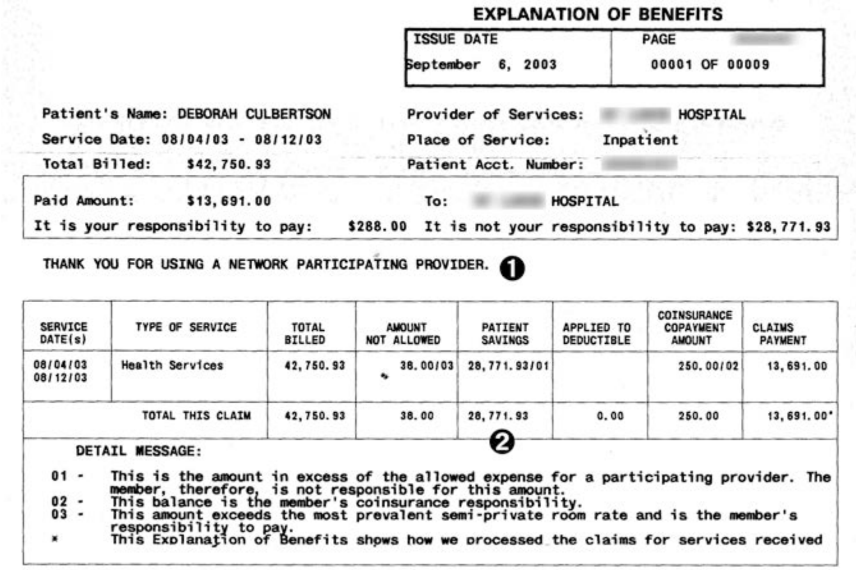
***Learning Opportunity**: Out of the stacks of out-of-network claims for the medical clinic staff working inside the same four walls as the in-network hospital staff, these three claims alone added $8,925.54 to our bill. Our insurance only paid $2,333,44.*

Over the next year and a half, the facility would try and try, bill and re-bill. When the bills finally rolled in over the many months ahead, we would owe over $30,000 from a one-week planned hospital stay that through no fault of my wife, and the great fault of the hospital and those working inside, turned into a three-month nightmare. Nonetheless, and fault not included, with my wife once again in a hospital, the billing clerk made a request that we increase our payments to $1,500 per month. With my insurance and other out-of-pocket medical bills, I was confronted with a healthcare outlay of almost $3,500 a month even as more medical debt piled on top.

As I know from my industry and personal experiences, once we pay the hospital, we will lose all recourse to seek a fair settlement for the circumstances under which we came to owe so much. Staring at my wife in a hospital bed, I tried to seek some semblance of logic regarding the facilities' convoluted billing. I was given a source for help. "Just call your insurance commissioner."

In another of my "change healthcare" volunteer efforts with the Centers for Medicaid and Medicare Services (CMS), I was honored to have helped start and co-chair the Southern Insurance Commissioners Task Force helping states themselves adapt to HIPAA. So, I had long before worked through that option. As the insurance company of my previous employer was in another state, my state had no ability to address the issue. As I was not a resident of the other state, that state had no ability to address the insurance issues of non-residents.

But at that moment, with Deb being operated on again, those were the least of my concerns. During the procedure, using yet another medical miracle, Dr. Sandy applied a special chemical marvel that in effect burns the lung against the chest wall. It cannot be used in every circumstance, but Dr. Sandy felt that this was the best option and that Deb would have an excellent result that would last. He promised Deb that he would do anything and everything he could to make sure that happened. He kept his word. The surgery went better than expected and worked perfectly. For the rest of her life and tragically other procedures ahead in Deb's journey, that magic glue kept Deb's lung in place and from ever collapsing again!



EXPLANATION OF BENEFITS

ISSUE DATE	PAGE [redacted]
September 6, 2003	00001 OF 00009

Patient's Name: DEBORAH CULBERTSON
Service Date: 08/04/03 - 08/12/03
Total Billed: $42,750.93
Provider of Services: [redacted] HOSPITAL
Place of Service: Inpatient
Patient Acct. Number: [redacted]

Paid Amount: $13,691.00 To: [redacted] HOSPITAL
It is your responsibility to pay: $288.00 It is not your responsibility to pay: $28,771.93

THANK YOU FOR USING A NETWORK PARTICIPATING PROVIDER. ❶

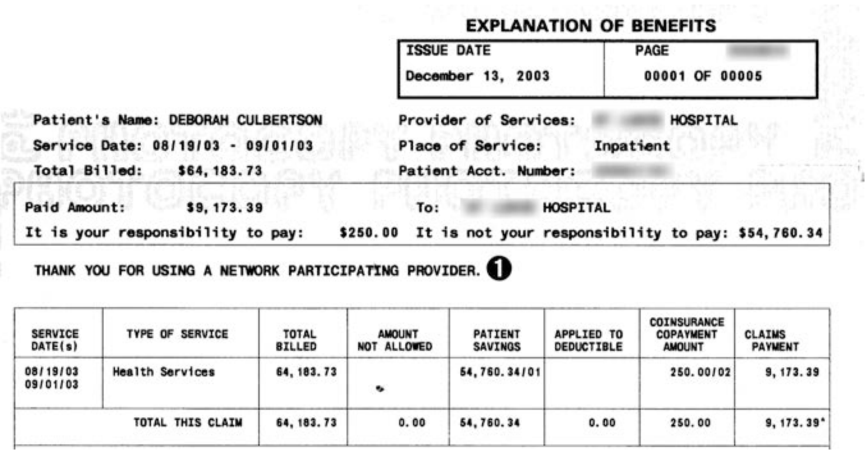
SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
08/04/03 08/12/03	Health Services	42,750.93	38.00/03	28,771.93/01		250.00/02	13,691.00
	TOTAL THIS CLAIM	42,750.93	38.00	28,771.93	0.00	250.00	13,691.00*

❷

DETAIL MESSAGE:

01 - This is the amount in excess of the allowed expense for a participating provider. The member, therefore, is not responsible for this amount.
02 - This balance is the member's coinsurance responsibility.
03 - This amount exceeds the most prevalent semi-private room rate and is the member's responsibility to pay.
* This Explanation of Benefits shows how we processed the claims for services received

***Learning Opportunity**: ❶ Unlike the clinic staff, the hospital staff working within the same walls, was in network. ❷ The hospital had to take a 67.3% reduction.*



EXPLANATION OF BENEFITS

ISSUE DATE	PAGE [redacted]
December 13, 2003	00001 OF 00005

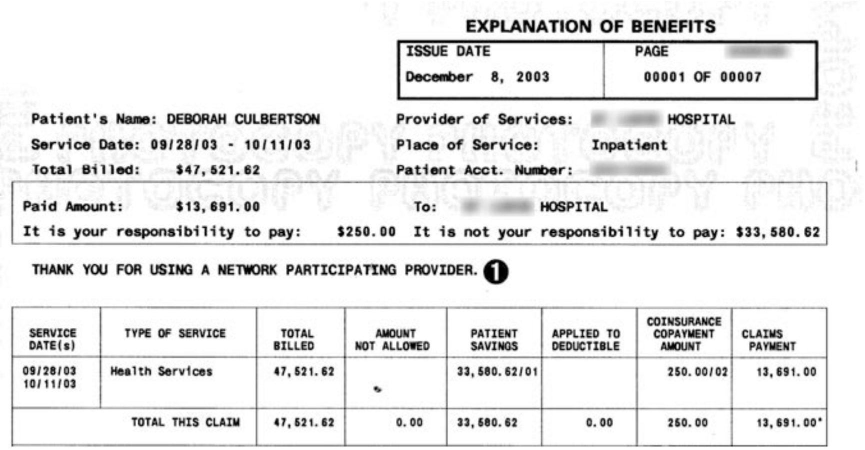
Patient's Name: DEBORAH CULBERTSON
Service Date: 08/19/03 - 09/01/03
Total Billed: $64,183.73

Provider of Services: [redacted] HOSPITAL
Place of Service: Inpatient
Patient Acct. Number: [redacted]

Paid Amount: $9,173.39 To: [redacted] HOSPITAL
It is your responsibility to pay: $250.00 It is not your responsibility to pay: $54,760.34

THANK YOU FOR USING A NETWORK PARTICIPATING PROVIDER. ❶

SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
08/19/03 09/01/03	Health Services	64,183.73		54,760.34/01		250.00/02	9,173.39
	TOTAL THIS CLAIM	64,183.73	0.00	54,760.34	0.00	250.00	9,173.39*



EXPLANATION OF BENEFITS

ISSUE DATE	PAGE [redacted]
December 8, 2003	00001 OF 00007

Patient's Name: DEBORAH CULBERTSON
Service Date: 09/28/03 - 10/11/03
Total Billed: $47,521.62

Provider of Services: [redacted] HOSPITAL
Place of Service: Inpatient
Patient Acct. Number: [redacted]

Paid Amount: $13,691.00 To: [redacted] HOSPITAL
It is your responsibility to pay: $250.00 It is not your responsibility to pay: $33,580.62

THANK YOU FOR USING A NETWORK PARTICIPATING PROVIDER. ❶

SERVICE DATE(s)	TYPE OF SERVICE	TOTAL BILLED	AMOUNT NOT ALLOWED	PATIENT SAVINGS	APPLIED TO DEDUCTIBLE	COINSURANCE COPAYMENT AMOUNT	CLAIMS PAYMENT
09/28/03 10/11/03	Health Services	47,521.62		33,580.62/01		250.00/02	13,691.00
	TOTAL THIS CLAIM	47,521.62	0.00	33,580.62	0.00	250.00	13,691.00*

***Learning Opportunity**: ❶ Compare and contrast these three in-network claims covering hospital services with the three out-of-network claims covering the doctors.*

Total Billed	*N/A*	*Savings*	*Deductible*	*Payment*	*Balance*
42,750.93	*38.00*	*28,771.93*	*250.00*	*13,69.001*	*288.00*
64,183.73	*0.00*	*54,750.34*	*250.00*	*9,173.39*	*250.00*
47,521.62	*0,00*	*33,580.62*	*250.00*	*13,69.001*	*250.00*
154,456.28	*38.00*	*117,102.89* ❷	*750.00* ❸	*36,555.39* ❹	*788.00* ❺

***Learning Opportunity**: The winners and losers at this spin of the healthcare roulette wheel? ❷ Hospital loses bigtime! It has to take 75.8% of their bill. ❸The Insurance Company wins. It only has to pay 23.7% of the bill. ❹ You win. ❺ BUT our deductible was low back then. Like many Americans, it has soared dramatically!*

The middle of the third week of October 2003, almost three months after the original surgery, one month before our COBRA would again run out, Deb was discharged once again. But we would now be confronted with another complex predicament—what to do about Deb's future care. Deb decided that even given the love and trust of her oncologist, Dr. Elizabeth, she would never again be put back in the in-patient hospital of the medical center. The fact was that we now knew only the four walls and the door of the hospital were in network, but doctors within the four walls from the medical center where Dr. Elizabeth worked, were NOT in the network of the insurance we were paying dearly for.

Ending in Transition

We ended October 2003, with Deb in theory cancer-free. With the tumor in her left lung removed, and the tumors in her right lung not showing any visible uptake of cancer, Deb was for the moment in remission. But Deb would never allow herself to feel that way.

"It's just a matter of time before it comes back."

Over the next month, as Deb continued to heal physically, this refrain became her mental mantra.

"If I don't know anything else, I know that I have not seen the last of this shit-ass disease. It usually comes back. I know it does from everyone I have seen get cancer."

Deb was badly shaken and traumatized from all she endured. Harkening back to her childhood days, she was also profoundly rattled watching the claims starting to roll in the door. Bank account death by a thousand cuts of insurance claims. More and more Deb started to talk about how the lives of her and her sisters had changed after they lost everything when she lost her father to the same disease. As Deb was so certain about her cancer prediction, it became inevitable that we would again stare at another complex healthcare and life predicament—what to do about Deb's care.

I struggled with the knowledge that even Jeff, the caring and generous CEO at my previous employer, could not this time again stretch me into another term of COBRA. But even if Jeff could help us in some way, the reality was that insurance now only covered the hospital but none of the doctors working in it.

I would have no choice but to go on the insurance plan of the healthcare company where I worked. In the convoluted non-system that is Healthcare in America, Deb would now be completely out of network. The company employee insurance was being provided by one of the health plan owners. Even though they are among the largest health plans in the state, the medical center was not in their provider network.

But in the end, it was not just the financial situation driving decisions. Deb decided even given the love, respect, and great trust of her oncologist, Dr. Elizabeth, she would never again be put back in their in-patient hospital facility of the medical center. She squarely now viewed physicians like Dr. Elizabeth, Dr. Sandy, and Dr. Todd, who long ago left, as the clinical exception rather than the rule. We both had lost all trust in the hospital.

That knowledge was a crushing blow on so many levels for me. I felt so much anguish and heartbreak for my wife and in turn, our sons. But as well, I was once again confronted with having to make my own transition to another job. Once again maneuvering to get Deb positioned in a place where she could continue to get the best and most affordable care by having insurance that would actually help pay for it. Even working for a company owned by two of the South's largest health plans, I was not immune from the labyrinth of complexity that can lead in an instant to being on the unlucky end of a spin of the great American healthcare roulette wheel.

But when it comes to Healthcare in America, it's not only about the doctors you want to have treat you, it's about where you work and whether your employer's insurance covers those doctors. The initial step of deciding where to try next for Deb's care fortuitously fell into our laps.

Earlier in 2003, I was speaking at a medical conference and had the great privilege of meeting Manoj, one of the most brilliant people I have met in my lengthy career. Since the conference, we had been speaking off and on, comparing healthcare notes, and established a business friendship. In addition to being very talented, kind, and compassionate, Manoj was a serial successful entrepreneur and had started a new technology company focused on leveraging the Internet in ways that had not been done before. Healthcare was one of the vertical markets where Manoj knew he could make a big impact. I very excitingly agreed.

Several hours away from where Manoj's company was located, there was one of our nation's medical centers of excellence. Years before I had outreached to that facility. At the time, while they did have availability, they did not accept our insurance. As luck would have it, that facility was still accepting new oncology patients and the insurance that Manoj had for his company was accepted there. He offered me the same position as I had with the healthcare technology company where I worked, Chief Technology, Security and Privacy Officer.

I had very mixed emotions. On one hand, I had great sadness for what I was leaving behind at my current position with a boss like Julie and an outstanding team and company I had helped build. Yet I had great anticipation of my being able to work alongside someone such as Manoj and his VP of Engineering, Gopal. He was another accomplished and exceptional talent I would be fortunate to learn from and work with. Unquestionably, Manoj and Gopal made one brilliant dynamic duo. I was honored to join them.

For the third time, I was changing healthcare jobs to have healthcare! As a family we were doing our best to prepare to make our third move, trying to stay one step ahead of the system and again seeking the Holy Grail—"in-network" insurance coverage at the best healthcare facility we could find. At least this time, however, it would be "when" and "if" Deb needed it.

Kindhearted and solicitous, Manoj very well understood our predicament. He not only gave me a new career opportunity located near a new healthcare opportunity for Deb, but agreed to allow us to take up to a year to make the move to where his company was located. I would be able to commute the twelve hundred miles to his office for meetings when needed and work from home the rest of the time.

Even with those life details resolved, and approaching Christmas 2003, Deb's mood still had not greatly improved. Normally, Deb was all about Thanksgiving and Christmas. Even during the last years entrenched in the battle, Deb still found her holiday spirit. But that Thanksgiving was just not the same. Very understandably, Deb was still shell-shocked. Even after engaging in our annual father-and-sons Thanksgiving Day "Clark Griswold exterior illumination" extravaganza, we did not elicit the normal cheering us on. Chevy Chase would have been proud of us. With the help of Steven and Thomas, I went even above and beyond our normal spinning of the electric meter. We added many more lights on the roof and new icicle lights around the roofline and more animated lawn figures to our menagerie of lawn illumination.

My friend Mr. Bill, who had become part of our T-Day family meal and celebration tradition since his divorce, even came over early and joined in on the fun, or at least as my sons would later describe it, "The supervising." We all did everything we could to make that Thanksgiving very special because we had so much to be thankful for with Deb having lived through all she did.

But it was not until our dearest friend Linda came for a visit that Deb would snap out of her doldrums. From the moment Linda walked in the door, the change in Deb was immediate. Linda has a very special way about her and is very gifted with people. All who meet her love her. One of the reasons Linda was one of the best of the best teachers. I was very grateful for Linda in so many ways.

But I felt as if I were trapped in an episode of *The Twilight Zone*. Images burned in my brain of the anguish of Deb's pain and continually seeing flashes of her lying in ICU for so many weeks and almost losing her. For weeks, hearing Deb moaning in pain from the nerve pain and other impacts of all the surgeries and chest tubes. The night before Linda arrived, finding Deb half-naked and slumped on the bathroom floor hysterically crying. At first, I did not know what had happened.

"Baby, what is wrong? Are you OK? Did you fall? What can I do? What can I get you? Let me help you."

Hearing my voice and looking up at me, Deb pushed my outstretched hand away and quickly turned away from me and tried to pull herself together, shielding her body from me and trying to cover herself and get the loose-fitting dress she had been wearing back over her head.

"Don't you dare fucking look at me. Don't you ever look at me again! Never!"

I started to help her pull the dress over her head, defying her orders. "Baby, I will never turn away from you. Ever!"

But Deb started crying hysterically and continued trying to push me away. Looking around the bathroom at the clothes strewn about, I realized what had most probably just occurred. Deb had mentioned earlier that day she wanted to get "dolled up" for her best friend. I slunk onto the floor next to Deb and wrapped my arms around her, trying to stay strong. When Deb finally gave in and tightly wrapped her arms around me and started to uncontrollably cry again, I could no longer hold back my own tears.

"I'm so, so very sorry, Baby. So very sorry all this happened to you. I wish I could just make it all go away."

Deb had finally and fully studied herself in the mirror and all that had been done to her to save her. She was trying on clothes and preparing for her best friend's arrival the next day and wanting to look her best. Trying to figure out what looked the best on her.

"I can't believe what they did to me. I look like fucking Frankenstein."

Deb placed not just pride, but great value in her model looks. She had dropped out of school in the ninth grade and was married and had her first son, Ray, at a very young age and quickly divorced and had to fend for herself. What she lacked in formal education, she more than made up for with street smarts and ability to survive. One of the things that helped her was her ability to leverage her good looks. Modeling was natural for her.

No matter what I said to Deb, I could not console her.

"You are still beautiful. In so many ways even more so than ever—you have to believe me."

But Deb did not, nor did she want to hear what I had to say. She saw herself in the mirror and nothing I could say or do was going to ever erase that. We sat on the floor for the longest time, until finally, Cody had enough! Deb had mothered him since he was a puppy and Cody was very sensitive and in tune with Deb. He did not like it when Deb was upset.

The whole time we were on the bathroom floor, Cody was on the other side of our bedroom door. I long ago had to replace all the interior door handles because Cody had figured out how to open doors by flipping the wave handles we had with his big furry mitt and pushing the door open with his head. I still don't know how Cody was able to turn that new doorknob on our bedroom, but all Deb could do was laugh through her tears as Cody came barging in and started bathing her face in licks until I stood up and helped her to her feet.

Less than a day after that torturous experience, now less than two months after being discharged from the hospital, I was back in *The Twilight Zone*. Here I was watching who I could only conclude was Superwoman in disguise. Playing and lovingly laughing with Linda. Seeing the two of them together was nothing short of magical. We all roared as Cody, now a fully grown moose after a year of steady growth, was well over a hundred plus pounds. He believed himself to still be the lapdog Deb helped spoil rotten. He greeted Linda by trying as hard as he could to get into her lap with her miniature poodle, Heidi. Cody had not lost his fondness for Linda or his puppy crush on Heidi. We all laughed and laughed watching the two of them run circles around each other in the backyard.

Etched in my memory is that afternoon and visit with Linda and watching her coax a "phoenix from the ashes." Such a marked change in Deb captured in a cherished picture I snapped of the two of them after Linda got Deb out for a shopping adventure. They came out of the bedroom dressed in matching white blouses, tan skirts, and tan boots, facing each other and holding hands for the camera.

Linda even got Deb to go out to a movie. Deb's first since her battle had started. Frequently going to the movies had always been such a beloved family time. But over the last several years, going out to movies had been relegated to a father-and-son respite. It was not just heartwarming, but a great relief to see how quickly Deb and her trademark humor returned. Watching as Deb's smile widened even at times at the expense of my dear friend Mr. Bill. He had developed quite a crush on Linda. Bill even joined us for the movie adventure and several times for dinner during Linda's stay.

Deb's sassiness was wonderfully once again on full display as we watched Mr. Bill stumble and fumble all over Linda and in return, Linda's stylish deflections of Bill's attention. Deb lightheartedly jabbed Mr. Bill throughout that he was barking up the way wrong tree.

After the movie, we all crowded into a booth at the local alehouse. I could only silently smile as Deb craftily maneuvered the boys onto Linda's side of the booth so that Mr. Bill was stuck seated on the outside next to me. At some point during the evening, Bill looked over at Linda, who was adorned in the evening sunset streaking through the window. Bill turned in my direction and whispered, "I'm looking at an angel."

Looking at Linda I saw more than just the beautiful picture Bill was looking at. Deb and I were so very blessed to have been indeed touched by this angel, given Linda's inner beauty, her heart, and great caring and love for Deb. We were so fortunate to have benefited from Linda's sage wisdom, strength, help, and advice over the years since I first met her at the boys' school library.

While not a match made in heaven for Linda perhaps, we were equally blessed for my best friend seated next to me. Bill gave much of himself, and he was another Deb and I could always count on. He had been put through his own personal wringer over the last several years, yet never faltered to be there.

I whispered back my confirmation, "You are correct, buddy. You are indeed looking at an angel."

I put my arm around Bill, leaning in. "You know, you may not be an angel, but you're pretty special too."

Typical of Mr. Bill, he launched into his Rodney Dangerfield routine. It was his unique way of deflecting what he viewed as faults or attention from serious moments including acts of gratitude for his friendship and caring. Now putting on his best Rodney face, voice, and hand gestures, Bill gave a show for Linda and Deb while the boys could only roll their eyes. Alternating between sips of his margarita, it all came out.

"Hey, I gotta tell ya. Everybody has hidden talents. They just don't know about them until they get a few of these tequilas down."

He continued, "I went to the bar to have a few drinks. The bartender came over. 'What'll you have?' I said, 'Surprise me.' He showed me naked pictures of my wife."

And, "My doctor told me to watch my drinking. Now I drink in front of a mirror."

Mr. Bill always came armed with a joke or one-liner, whether at the local watering hole or out on the golf course. After Thomas made the middle school golf team, we started joining Bill as we could for a Sunday morning "rounds of duck" at a local nine-hole golf course. At the time Thomas took an interest in the sport, I had never held a club before. Fortunately, Mr. Bill was an experienced golfer. It seemed a great way to get some exercise, further Thomas's ambition, and introduce the sport to Steven. More importantly than anything to me, we got to spend four hours of alone time together, with our biggest life-fret at that moment being a little white ball. Those golf outings became a mission and time of camaraderie and respite for our own battle with all swirling around us.

After Linda's visit, we had another visitor that would help keep Deb's holiday spirit on track, our mom, Jeanne. In short order, Mom and Deb had the inside of our home as decked out as the decorations that adorned the outside. Shortly thereafter, we were able to make the drive for our first time in a couple of years down to Jeanne and Ken's home. We had a wonderfully warm Christmas and celebrated a peaceful start to the New Year that helped us settle into the realities of our new future.

As the bills for the almost three-month nightmare started in earnest to roll in, I tried once again to stay one step ahead. Even with my obviously abysmal lack of luck spinning the healthcare roulette wheel. Amazing, but not, given the absurdness of our non-healthcare system, our new insurance from Manoj's company would completely flip. This time we had coverage that would be accepted by the medical center, but not at the hospital facility they contracted with.

Deb was steadfast in her anger and fear of ever being put back in that hospital again. But at least her doctors, most specifically and only in her eyes at that moment, Dr. Elizabeth was now again being covered. We decided to gamble that Deb would not need major new care through the rest of the school year before we could transition. I would start traveling to the new job until the summer, when we would make the move.

The Year of Peace and More Transition

As we started our 2004, Deb's major health challenge continued to be the pain and discomfort from the surgical sites and rib cage discomfort. Hurting her most was the large, scarred, indented area that resembled a crater—the remnants of the initial chest tube that had impaled Deb for many weeks when her left lung would not close and then became badly infected after Deb was given MRSA. Even with some pain and discomfort, however, Deb was still determined to get completely off all the drugs!

With my traveling and Deb maintaining, the first quarter of 2004 blew by. But for the first time, Deb was uncharacteristically anxious awaiting her next checkup scheduled the first week of April. While understandable perhaps for most under such circumstances, not for Superwoman, however. No matter what was happening in the battle or result Deb was awaiting, she was a rock. But the closer to the appointment date, the more nervous Deb became. She even talked about putting off the appointment at one point, only to relent.

Fortunately, her concerns turned out for naught. After the scans and bloodwork were completed, we once again sat in Dr. Elizabeth's office. After she gave Deb a thorough exam, listening to her heart and lungs and reviewing the scans, she turned to us and rendered her verdict with a broad smile.

"Everything is looking really good. Your bloodwork and scans, and your lungs sound clear and your oxygen levels are excellent."

But as Dr. Elizabeth looked at the scars on Deb, and the chest tube site, she lost her smile. She held Deb's left hand, now studying the two nasty-looking scars that had formed from the PICC lines used at the hospital to deliver fluids that also became infected. Those scars crushed Deb, unlike the crater in her back. She could hide her back. She could not do so with her once-beautiful hands short of wearing gloves in the South.

In a very soft, very caring and kind-spoken voice, Dr. Elizabeth said to Deb, "I am so sorry. You have been through so much. Your body is going to take some time to heal."

Exhibiting all the reasons we had such great trust and faith in Dr. Elizabeth, she not only spent a good deal of time examining Deb but a good amount of time talking to her about her hospital experiences. She also discussed Deb's on-going pain control and the importance of closely watching the surgical sites, especially given her MRSA. Dr. Elizabeth suggested Deb continue to use the silicone sheets and gel on the chest tube site and as well on her hand wounds.

In preparation for our move, Deb and I had discussed before her appointment speaking with Dr. Elizabeth about transitioning her care. We also needed to inquire about the safety of Deb making plane flights. I was surprised, but then again not, when instead Deb simply inquired, "Would it be OK if we went on vacation this summer on a plane?"

Dr. Elizabeth shared with a big, toothy grin, "Unless you are having any complications, I think it would be a great idea to go on a nice vacation. If anyone has earned it, you two and those boys most certainly have!"

Looking over at Deb, I just went with the flow. I had wondered if she was truly ready yet to tell Dr. Elizabeth. While she loved her and trusted her dearly, Deb was scared to death of the hospital and now the insurance company.

We were so relieved to hear the next words that came from Dr. Elizabeth. "Let's plan your next follow-up for six months. So I'll see you back in September and we'll run more scans to see how things are looking everywhere!"

Dr. Elizabeth also made certain that Deb knew one more thing loud and clear. "If you need anything or something changes, you know how to reach me." Dr. Elizabeth had long ago given us her personal contact numbers.

While few episodes of *The Twilight Zone* end well, this for the moment would be one of those episodes. Even given all the months of torturous procedures, pain, and worry, as Deb always managed somehow to pull off, she emerged through the other side of one helluva long, dark tunnel. We celebrated by taking the boys out to our family favorite restaurant, Carrabba's. For the first time in over three years, we enjoyed a family gathering with the intense pressure of at least the care side of the battle abated.

As April 2004 vanished as a blip in time, Deb was now nine months in remission and cancer-free. During the months ahead and throughout the rest of the spring and into summer, Deb continued to heal and the pain greatly subsided. Unless Deb moved a certain way or twisted her body, putting stress on the crater in her side from the chest tube wound, she was in relatively low pain. Despite all the press that had even back then dominated the news about this particular pain med, Deb easily weaned herself off. She now only needed a small dose, usually at night, preferring to mostly use over-the-counter (OTC) inflammation remedies.

Given Deb's allergy to morphine, even and at times awfully damn difficult and costly to obtain, it was a godsend. Deb tolerated it well. It worked on her pain without making her groggy. But it did come with a high price tag—not just in dollars, but part of her colon and an extra surgery.

We were for the time being blessed with no doctors' visits. No 911-ambulance calls had to be made. No constant runs to the pharmacy. There were no appointments with the lab for blood draws or imaging center for scans. But peace in our life was not to completely be. The care side of the battle was now fully giving way to the financial side of Healthcare in America. What had once been a mere battle with the insurance company and the billing offices of the medical center and hospital was now a war unto itself. I even enlisted some of my dear professional colleagues into the battle.

Of all the kind help we received, unquestionably the standout and star quarterback was David. He was one of our early hires at the healthcare organization I had just left. We had been fortunate to have lured David away from one of our health plan owners. David had the huge task and great success of setting up and running our provider customer service and support that would touch almost every doctor's practice and hospital in the state.

David was an expert in insurance fine print and nuances of claims processing across insurance companies. He greatly advised me how to resubmit some of Deb's claims and get others re-categorized and repriced, including some claims under "emergency-care provisions" that sometimes exist in policies. Even though we still had one crushing medical bill, it could have been much worse without David's help and the thousands and thousands he saved us. Deb and I were deeply grateful for all of his personal time and great caring he bestowed upon us.

After the boys got out of school, we made a couple of family road trips. First, we made a family cruise to Deb's family for a few days. Then Deb and I made a day trip together. It was our first solo outing since Deb was on the magical chemo pill trial. We traveled two hours west to visit my aunt and some of my cousins. We were extremely close to my Aunt Margie and my cousins Sue and her brother Dean, who was the best man at our wedding. Since the beginning of the year, we had grown more and more distraught and concerned over what was happening with Sue's health.

While Deb, for now, was on one side of the cancer battle, my dearest cousin Sue was tragically on the other side. She had many bouts of strep throat over several years. But at the end of 2003, Sue complained of even more throat pain and soreness. As her throat continued to get worse, she was challenged to obtain a clear medical opinion and got nowhere, except repeated diagnoses of strep or some other viral condition.

The beginning of 2004, after months of struggle, Sue was finally diagnosed with uvula cancer. Sue was six months into her battle as we visited her that mid-June. It was difficult for Deb and me and we were devastated. Sick from chemo and hoarse from radiation, Sue shared with Deb all she had endured. The girls exchanged details of their journeys and war stories. Sue had undergone a procedure to remove her uvula, as well as many rounds of radiation and chemo.

It was wretchedly heartbreaking hearing them talk about complications suffered from radiation with neck and throat pain and swelling. Both had great difficulty trying to swallow and described radiation burns far worse than the worst sunburns either had ever experienced under the sun. They shared stories from the battlefield and Band-Aids that may or may not work.

They anguished over battlefield scars and collateral damage. Two combat warriors facing the consequences of doing battle and how to deal with the incoming barrage of sickness, loss of appetite, stomach problems, and great fatigue. Repeated trips into and out of the hospital, itself a battlefield on another front where more potential landmines could be stumbled across.

At the end of a very long day, as best as they could, the two warriors hugged each other tightly, both promising not to give up the war and continue with each and every battle until the war was won. They also promised to do a better job calling each other and keeping in touch. On the way home, Deb's concern and pain for Sue were evident in her distressed face. She spoke little except to thank me for insisting that we not take the boys with us that day as she had wanted. She left me with a haunting statement in the form of a question to herself.

"I know that was me not too long ago; I don't want the boys to ever see me that sick again. I really don't know what the hell I would ever do, facing all that shit again."

That visit unquestionably took much of the wind out of Deb's sails. She was very distressed and despondent, as I, over Sue. It seemed as if something inside her snapped. Deb had always made it clear that she expected her cancer would return.

"Because it always did!"

I believe looking back, based on many of the things Deb said and did afterward, she started to dwell on the possibility of the battle raging again evermore.

Now almost mid-summer, Deb and I boarded a plane for our twelve-hundred-mile flight to the state and town where my new job was located. We would still be a few hours away from the new medical center where we had planned to transition Deb's care. But we determined to cross those bridges or highways <u>if</u> we had to. We decided given all that we had to accomplish in a very few short days, we would not take Thomas and Steven with us. My parents had long wanted to spend time with their grandsons, so it turned out a win-win for all.

Unquestionably, Thomas and Steven were not at all pleased about moving again and leaving their school and all the friends they had made. But as the strong and supportive sons they were, I could see they once again would go with the flow as they had with all the other moves we had made. Once again, jockeying for position as we tried to get their mom the best healthcare we could. Spending time with their other grandparents was a great way to ease moving trepidations.

But it was obvious even before we arrived at the airport, Deb was very uneasy. She was uncharacteristically quiet and lost in her own thoughts during the journey. We had talked about her lungs before we got on the plane and Deb did not seem to have that as a concern. She said her lungs felt very solid and every day she had continued to use a spirometer to exercise her lungs. A spirometer is a device letting you play a game of inhaling into a mouthpiece connected to a cylinder trying to keep the float in the cylinder between two arrows while you continue to inhale. Deb's breathing was incredibly strong even with a large section of her left lung removed. She at times kicked my butt and that of the boys on also trying out the spirometer. Deb got to be a pro at using it. She was amazing.

On the flight, I tried to get Deb to open up about what was really on her mind. She seemed unconcerned about the boys being with my family and knew they would have a much better time with their grandparents. All she would do was make small talk and express some concerns about her Cody-bear being left alone. But Mr. Bill had volunteered to keep checking in on him and several times a day going over to let him out and feed him. He also was prepared to stay over a few nights. So I had hoped that would resolve Deb's uneasiness about leaving her now-almost-one-hundred-twenty-pound baby.

But I saw it written all over her beautiful face, the enormity of the transition and leaving her mother, her sisters, and family, to say nothing of the care of Dr. Elizabeth. We had a lot to accomplish in the few days that I had jam-packed with activities including looking at some houses, schools, and making the drive to the new medical center and their cancer facility.

In the months prior, I had scouted out areas to the east of Manoj's office and in the direction of where the medical center was located two and a half hours east. I found some locations in nice communities and schools and had some homes lined up to look at. While translating still into a sixty- or ninety-minute drive to work each way, I could cut the distance to the cancer facility almost in half. We would be ready <u>if</u> Deb needed it.

Once we landed and started traveling about, Deb became a little more engaged and into the experience. Especially when we were looking at the homes and Deb got into the feature details and discussions with the realtors. I had picked some of the more popular eating spots in an effort to make it an engaging time exploring around the area. Sadly, Manoj was out of town as I recall, so he and Deb did not have the chance to meet.

We saved the trip over to the medical center for our last full day we were in town. But on the drive over, Deb once again drew quiet as she as well kept looking about at the terrain. I knew part of the reason was that Deb had lived in the town we were headed for a year when she was much younger, before we met. She had a bad experience from the get-go when her moving truck was stolen and she lost all of her possessions, including many irreplaceable items, pictures, and documents.

Once we arrived in the vicinity on the outskirts of the large metropolitan area near the medical center's cancer facility, Deb was clearly not impressed, focusing initially on the heavy traffic. At the cancer facility, Deb very carefully studied everything, saying little. I was stunned, but then again knowing Deb I should not have been, as Deb walked directly up to several obvious patients of the facility. She grilled them in a polite way about their thoughts regarding their care and their doctors.

I was very relieved as we heard nothing but glowing reports about the medical center, hospital, and their cancer facility. We next stopped at an administrative office and obtained the patient forms that we needed in order to have Deb's records transferred there and start the process of verifying our insurance so we could get her first appointment scheduled. It was another long, silent drive back to our hotel. Deb was evasive as I tried to obtain her thoughts and she was otherwise non-communicative our last night at the hotel. That continued as we packed up and headed to the airport the next morning.

On the flight home, I tried bringing Deb out of her silent shell, but to no avail. When I ordered a drink, Deb uncharacteristically chimed in to our stewardess, "Make that two." I could not recall the last time Deb had a drink.

I wondered what was going on behind those beautiful blue eyes that were scrunched and fixed straight ahead. Deb kept her answers brief as I tried to nudge out of her what she was thinking. I wanted to hear her thoughts or concerns about the new medical facility, the town, or the houses we had looked at. It was more evident with every sip of her drink and her choppy responses this was not going to be a good time to solicit her thoughts. I mostly found myself staring at the back of the seat in front of me and out the window of the seat next to me.

Can We Move Forward

Deb's demeanor changed dramatically once we arrived home, especially as she had her Cody-bear back. From the way Deb and Cody carried on when we walked in the door, one would have thought we had been gone a year. She fed him so many biscuits that night along with his milk. "Biscuit-butt" earned his other nickname on his way to delightfully snuggling up on Deb's side of the bed at her feet once more.

Waiting for the dust to settle, I finally had a chance to sit down and debrief with Deb about the trip. Deb seemed both resigned and willing to become more engaged regarding the move. She insisted on taking the lead, working through selecting a new home and finalization and the start of our moving details. It was a critical time for the healthcare product line I was leading and Deb being well enough and motivated to help was a blessing. I also knew this was going to be difficult enough so I wanted anything that would make things the best they could be.

"I don't really care which house you choose, Baby. I am good with whatever you decide," I told her. "Just work the details and then let's tag-team the final price and offer."

As the weeks stretched on, however, Deb made little headway. I did my best to let her manage things, but we were way behind where we needed to be in time for the start of the school year. I was sensitive to having to move our sons after school started as that had happened so many times to me and my siblings and cousins growing up as Army brats. It was now almost mid-August and we needed to make an offer on a house immediately. But I decided to let things go a few more days, until after we celebrated Deb's 47th birthday.

To my surprise, Deb did not wish to go to Carrabba's as she typically did. She wanted to go to my favorite restaurant, a crab house that featured Maryland-style blue crabs. My great love for them was honed by growing up as an Army brat and spending lots of time at Ft. Meade, where Dad was often stationed, and as well having a mom who hailed from Baltimore. We always went to live there near my mom's mom, little Gram, and her brother, Uncle Cal, when Dad was sent to places we could not go. Such as Dad's two tours in Vietnam.

Further surprising me as well as our sons, Deb gave Thomas and Steven a crab reprieve. They did not have to sit for a couple of hours watching their old man pick and grin.

"You boys get to celebrate my birthday by ordering pizza! We'll have the cake and ice cream when we get back from the crab house," she said, to the glee of the pizza-brothers.

We found the crab house almost day one when we were scouting out what part of town to settle into when we relocated to get Deb in the medical center. When we spotted the crab house restaurant, we knew this was the right area of town after stopping there for dinner. We picked a home in a large planned development nearby with great schools. Over the years, we ate there a lot, and I many more times to get the crabs to go when Deb was too ill to eat them or go out. Deb used to tease me we should have owned stock in the place.

Cindy, the crab house owner (with her husband, Joe), was very pleased to see Deb once again and she greeted us with her trademark hug. Cindy was genuinely surprised to see how wonderful Deb looked as I had shared many updates with her over the year as the caring and dear friend Cindy had become.

"My goodness, Deb, you sure look beautiful. I am so happy you are through all that hell. You look absolutely ravishing."

As we sat in our usual quiet place in the back across from the small bar, I was surprised once again as Deb ordered a drink and added, "I'll go easy on you tonight, Babe, so you don't have to pick any crabs for me."

Deb ordered crab cakes with the Maryland crab soup we always had as an appetizer. Deb developed a fondness for blue crab meat. But not so much the blue crab picking! We toasted her birthday and talked about all she had endured since her last birthday, just after her first lung surgery. It was a birthday party and celebration Deb could not remember at all.

I am not certain which crab I was picking and grinning on when Deb suddenly, and without warning, hit me straight between the eyes as if making casual dinner conversation.

“We can’t move! I don’t want to make the move. I don’t think we should move the boys again. They have a life they love here and I don’t wanna move them again. I don’t wanna move that far from Ma, either. I just can’t. I also don’t want to go back to that state. I had too many bad feelings about the place on our trip. I thought I was over it but I’m not.”

I had a suspicion I would be in for something that evening based on the setup. Deb wanting to go to the crab house instead of her usual birthday dinner and leaving the boys home for the first time ever for her birthday. But I never saw this coming. I was totally blindsided and sucker-punched. While I should not have been surprised, I was completely and thoroughly dumbfounded.

“What about your care? What if you need to go back to the hospital?”

Deb was ready for my questions and responded without hesitation. “Our insurance will pay for Dr. Elizabeth and she is the only one I am going to see.”

Then she drew a deadly serious look on her face. “I ain’t going to be going back to that damn hospital for nothin’! Never!”

My mind started racing, at what Deb was sharing and her answer. But the look on her face concerned me as much as anything she was saying. Deb knew as I quietly returned to picking through my crabs that I was lost in it all. Deb gave Cindy the high-five for another round of drinks.

“I’m really sorry, Babe. I really am! But we just can’t move. I know this is going to create problems and a mess for you and for us.”

She reached over and put her hand on my arm. “You have done so much and I have put you through one helluva of a ride, I know.”

I was still struggling with what to say as my mind was now fast-forwarding past the care and insurance challenges, to another huge dilemma—my job.

"Well, Baby, I don't know what to say. I guess we'll work it out somehow. We always do. All I know is today is your birthday and you are still here with me and our dudes."

Cindy could not have timed it any better as she again personally delivered our next round to the table and inquired about the crabs. "Delicious as always," Deb cheerily said to a beaming Cindy. As if nothing that had just happened had occurred. After Cindy left, Deb held up her drink.

"So cheers, Baby. Here's to many, many more birthdays ahead," she said, and we clinked glasses. But our eyes locked as Deb kept hers fixed on me. I suppose looking for some sign or a crack in my armor.

Over the next few days, I had such mixed emotions ripping me apart. On one hand, I didn't really want to go through another move either and put the boys and ourselves through that. I really did not want Deb to lose the care of Dr. Elizabeth. I also had grown to love the town, neighborhood community, and the home where we were living.

But, on the other hand, I was deeply concerned about our insurance situation and I was enthralled with my new job and the company that Manoj was building. I had the career opportunity of a lifetime, working with some of the most brilliant talents I had worked with in my career. We were developing foundations that I truly believed would make a difference in healthcare. I had a dream job working with a dream team.

But as was part of my employment agreement, I had made a firm commitment that within a year, we would move. Over the previous months, I had been on the road, or more appropriately, in the air, traveling back and forth to the office more often. Still small, yet rapidly evolving and developing, the company needed a Chief Technology, Security, and Privacy Officer that was in the office and interacting on a daily, face-to-face basis with the rest of the team—not twelve hundred miles away.

For the second time in my career, in less than a year, I had to face another of the most difficult discussions I ever had to have in my career. This time it was with Manoj, not Julie. As always, he was extremely understanding of my family situation. Manoj suggested the possibility that I remain in the role of Chief Privacy Officer and asked me to consider it.

But with the duties and responsibilities of the lead privacy position given healthcare security and privacy requirements and the nature of what we were developing, my being based remotely would lead to Manoj paying significantly more funds for my travel while producing an outcome not as superior as if I was ingrained with the team and the application development.

BUT, I was concerned not only regarding the travel impacts on my effectiveness and costs to Manoj, but the thousand-pound gorilla that hung over Deb and me like the dark, seemingly inevitable, menacing cloud it was.

"WHAT IF?"

"What if—the next visit with Dr. Elizabeth is 180 degrees from the last visit?"

"What if—the battle starts again?"

As the potent problem-solver and visionary that made him so successful, Manoj not only graciously accepted my decision but also—showing his heart and belief in me—offered an alternative that is still with me until this day.

"Walt, what were you doing prior to Debbie becoming ill?" Manoj inquired.

I was thinking he was familiar with my background, so I was certain he already had the answer. "I was an independent, working through my little consulting company, Manoj."

"Given the situation with Debbie, and the need to be able to base yourself out of your home town and office, would that not be a good opportunity for you now? Return to consulting again?" Manoj inquired.

In all the things that were flowing through my mind in those days since the discussion at the crab house with Deb, that was one alternative I really wasn't thinking of, given the challenges of trying to get health insurance as a self-employed individual in America. Health insurance was always a continuing and looming nightmare dogging me throughout my entire career, given my propensity to be self-employed. Now with Deb's preexisting conditions, cancer and

MRSA, we stood ZERO CHANCE of getting anyone to reasonably cover us. My days of self-employment were over, or so I thought.

But as Manoj was sharing his thoughts, one popped in my brain immediately. I could go back to being on COBRA through his company. At least Deb's beloved Dr. Elizabeth would be covered, in theory, for another eighteen months. Although I also now knew, now more clearly than ever, when it comes to health insurance, that promise of coverage is only as good as the next renewal cycle. The relationships between your company who picks your insurance and your doctors and hospitals can and will change and you have <u>zero</u> control.

"If you like your doctor, you can keep your doctor."

No one who really understands how health insurance in America really works would dare utter that statement. Even with all my years in the business and working directly with insurance companies, I still learned that the damn painfully hard way. We were now caught in a complex web of those mistruths.

But Manoj had more surprises in store for me during our discussion, offering me two opportunities that left me literally speechless.

"There are still many opportunities you can contribute to. We can switch you to project-based and piecemeal efforts that you can accomplish, continuing to work with the team, even from remote!"

Pausing only briefly, Manoj added, "So if you decide to go back to independent consulting, Walt, I want to become your first client!"

What he added next put on clear display again the kind of caring and heartfelt entrepreneur he was. "I want you to stay until your one-year anniversary. You will be vested and eligible for at least that portion of the stock options under your employment agreement. Also, we still need you, Walt. It will take some time to replace your roles, and we need a thorough transition. We can turn this unfortunate situation into a win-win for both of us."

When I gave Deb the good news, she became very emotional. "I was really worried what I was doing would not end well for us. But you came through for us once again, Baby."

But I did not feel as if it were I who had come through. It was but another very compassionate soul who I was blessed to have had as my boss and mentor. The lucky job streak would continue. I had kept in close touch with Julie and the team from the healthcare company I had previously left. When I shared my updates, I received a surprise call the following week from Julie after she heard the news. Before I knew it, I had my second customer. But as my employment status also drifted to the health plan owner of Julie's company, before I knew it, I had my third customer waiting in the wings.

Could It Be Starting Again

The beginning of September, a couple of weeks after her birthday and with the big decisions made, Deb had her six-month follow-up with Dr. Elizabeth after having her standard bloodwork and imaging. Unlike her appointment six months prior, Deb did not seem nervous about this appointment except for her normal anxiety about being placed inside the CT (computed tomography) tube. She was extremely claustrophobic. Otherwise, Deb was very pleased we were not moving anywhere, and that seemed to be carrying the day and any apprehension that Deb may have had.

During those weeks leading up to her checkup, however, I was the very anxious one. While I did my best not to show it, on the way over to her appointments that morning, Deb reached over and put her arm on my shoulder. She carefully leaned over closer to me, not wanting to twist her body too much and putting stress on her "crater." Deb was always able to read me like a book.

"I know you've been really worried, but everything will be OK, Babe. No matter what Dr. Elizabeth tells us, everything will be OK. OK?"

But my concerns were not entirely unfounded. While this time the appointment was not as I feared, 180 degrees different from the last prognosis, sitting with Dr. Elizabeth, she delivered news that for me was at least ninety degrees different from six months prior. After closely reading and interpreting the results of the new tests and scans and examining Deb carefully, Dr. Elizabeth did not turn to us with her trademark toothy smile. Instead, she very softly stated, "Well, everything, for the most part, looks really good. However…"

I sank into an immediate internal panic as my heart started racing. I did not want to hear that word. I was frightened as to what would come next. Would we once again hear the two most dreaded words in healthcare, “I’m sorry?”

Dr. Elizabeth continued. “But I do see one very small spot in the original area of your right lung. At this point, I would say it is inconclusive, especially given the radiation scarring in that area.”

I was torn between two strong competing forces, one of hopefulness, and yet I was extremely disheartened at what Dr. Elizabeth just shared and what she suggested next. This was always the opening salvo at the start of another battle.

“I think we should see you back again in another three months and get another CT scan on you and also use contrast and see if that area is any more pronounced.”

A computerized tomography (CT) scan uses an X-ray beam that moves in a circle around your body at different angles as you lie on a hard table inside a large round cylinder. The X-rays create a series of cross-sectional images (slices) of your bones, blood vessels, and soft tissues such as the lungs and inside of the chest.

Because Deb was highly claustrophobic, these could be very troubling procedures for her. Especially when she was getting a full-body scan with contrast as they take much longer to perform. For those procedures, Dr. Elizabeth wonderfully prescribed Deb mild sedation to help relieve some of her anxiety as she was slid into the CT tube for well over thirty minutes.

It was a long drive back home. The talkative Deb that was seated to my right on the way over to see Dr. Elizabeth was no longer talkative. Deb focused stone-faced out the window and down at her scarred hand. Most of the way back home she remained silent, as did I, not knowing what to say or how to soothe. I chose instead to let her absorb and process the battle report. Just before we arrived home, Deb turned to me, reaching for my hand and resting hers on my leg.

“It’ll be OK, Babe. Everything will turn out.”

As I stopped at the four-way stop sign near our subdivision entrance and gazed into those beautiful, yet hauntingly pained blue eyes, I knew those words were meant for me, not how she really felt. I had stopped long enough for the car behind us to thankfully blare their horn, breaking the silence and a waterfall of tears that were coming had we stared into each other's eyes another second.

The horn also broke Deb's brief silence. "I don't want to say nothing at all to the boys or anyone else, especially Ma. I don't want anything said, especially to her. OK?"

But I was not "OK" with it. I loved Jeanne too much and had promised her long ago I would keep no secrets from her. I didn't know what to say. I didn't know what to do. But I absolutely had to pull myself together. Especially as I knew the boys would be home from school shortly after we arrived and in that part of Deb's demand, I was in complete agreement.

Meanwhile, Deb was her typical Rock of Gibraltar. She even decided to put the three-month appointment off another month until after Christmas. She set her next appointment with destiny for January 6. It would be one heck of a way to start out 2005.

Over the weeks that followed, I formed a new corporation and started another transition, back to being self-employed and back to clocking and kicking the insurance can down the road for another eighteen months on COBRA. As typical, it came with a high price, this time $1,046.01 a month. But at least that was $400 a month cheaper than where we ended up the last time we were on COBRA. While the insurance would for a time cover her doctor, I had no idea what we would do if Deb had to go back to the hospital even if she would go back there.

But I knew I needed to get my ass to work to figure out a plan. If I had not learned anything else in this new healthcare education I was immersed in, the healthcare winds can change very suddenly and whisk in your direction unforeseen and tragically treacherous storm damage. For now, and not knowing what was to be, I dived back into my work setting up my new company, trying to stay focused on anything other than that little spot in Deb's right lung. Deb equally did not want to talk about that little spot at all either. She went straight back into what had become her normal routine over the past year.

Deb was bewitching as she beamingly handed out candy to the throngs of neighborhood children that always appeared on Halloween. Over the years that was always her "job" while I took the dudes out to walk whatever hood we lived in at the time. Once our sons were old enough to not have their old man tagging along, I got to stay home and witness Deb in action. She so enjoyed interacting with each and every trick or treater—big or small—complimenting them on their costumes and pretending to be afraid of those who wore scary outfits, and oohing and ahhing and making over the little girls in Cinderella and princess costumes. After a couple of years of not wanting or being able to go to the door, it was such a wondrous moment watching Deb engaged in magic again.

Even with all I knew must be racing through Deb given the uncertainty of it all, she remained so stoically calm. A calm I know I could under no circumstances muster. Even with a new date with destiny looming, Deb was resolute. She again took control of Thanksgiving dinner. Most years before Deb got sick, she would always cook the bird while the boys and I put up the Christmas lights and yard decorations. For the first time in four years, it was delightful to see her back at the helm of the kitchen.

Christmas was as equally enchanted. For the second time in two years, we were able to make the drive down to Jeanne and Ken's home. We had another big family Christmas party to celebrate the holidays, as Deb's family often did. This year it was not the typical family gathering that Jeanne and Ken always hosted in their large, stylish home. Ken had transformed their once small, modest abode over the decades from a tiny, barely two-bedroom house into a splendid palace. Ken's master construction skills were venerable. Mom and Dad hosted a Christmas party that was for all a special celebration of Deb.

Jeanne came from a large family of seven children of which she is the matriarch. Over the years, Mom's family had one by one migrated out of Chicago to head south. They all lived within a couple of hours of each other. I was so fortunate that when Deb came into my life, so did an entirely new and loving family, including most especially another mom and dad. In every way other than giving birth to me, they are fully my parents. Blessed am I to have had two moms and two dads.

Of all her aunts and uncles, Deb was particularly close to Mom's youngest sister, Shirl. Aunt Shirl was a nurse and always there for us. From the start of Deb's battle, she and Deb communicated more frequently. Aunt Shirl was a godsend and always a wealth of information, love, and support. More than any of her siblings, Aunt Shirl is the closest to Jeanne and Deb in personality and outgoingness. Everyone who meets Aunt Shirl loves her, one of the reasons she is so successful in her part-time, non-healthcare line of business as a travel agent.

That visit was dreamlike in so many ways. Yet I struggled at times, trying to keep the dark clouds hanging over my head at bay and invisible to those around me. Watching everyone together and gathered about Deb was uplifting, as was taking refuge in Ken's comedic skills that were on full display. He was always the proverbial life of the party. Over the decades of traveling for Walgreens building so many pharmacies in so many locations around the country, Dad had collected an arsenal of material. I marveled and roared over how he could remember so many jokes, which he always adorned with accents and movements as he told each hilarious and, at times to Mom's chagrin, risqué stories like the one he had given to Deb that she had shared with my dad and me at the conference.

But it was most difficult breaking my promise to Jeanne on the orders of her daughter. The night before we had left home, I made a comment about not knowing how we were ever going to keep what was happening from her mom. Not only could her daughter read me like a book but also so could my other mother. Deb and I had a very intense discussion about her decision to not inform her mom about the latest test results and her appointments scheduled after the first of the year.

"You'd better damn figure out a way to keep it from Ma. We are going down for a party and we are going to keep it that way. You gotta be your normal self or Ma is going to know something is up."

Over the years, I had witnessed this from Deb from time to time. I never completely understood why Deb had so often wanted to keep her mom in the dark or away. Admittedly, though, we did not know whether we were staring down the return of cancer yet, so I resigned myself to that logic. Why should I ruin Mom's Christmas and unnerve everyone else when we really didn't know anything yet? Right?

The truth was, however, there was a reason in the weeks leading up to that Christmas trip I had become more and more concerned as January 6 approached. I started to notice Deb's fingernails over the past months slowly changing. They appeared to me to be curling once again. That was a classic, telltale sign that her HOA (hypertrophic osteoarthropathy) was returning. First came the curling of her nails, next came the clubbing, and finally the great swelling and pain.

Deb had the most beautiful hands and natural fingernails. She always kept those of medium length and well-manicured. One of the reasons she was so upset about the two large scars on her left hand. She had even modeled her hands and feet in a couple of photoshoots back in the old days. Deb's friends and many of our female family members were jealous. She never had to go the "salon" nail route. Deb was as distraught about the changes in her hands and feet as much as the other collateral damage stemming from the battle.

I also had noticed that Deb was more and more frequently rubbing her thumbs across the tips of her fingers as if she were rolling something. I would find out later that we weren't hiding anything from Jeanne. Even though she let it go, Mom had also picked up on the changes in Deb's hands. Jeanne had observed this in her daughter since the start of her cancer battle. She knew this ancillary lung cancer disease, HOA, very well. Mom had lived through this with Deb's dad when she lost her husband to the same disease and the same progression of his HOA.

Three days after Christmas, we headed back home to celebrate our nineteenth wedding anniversary. We never liked being on the road New Year's Eve, always preferring instead to quietly ring in the New Year at home. But as I listened to the ball drop, it was not with the same enthusiasm as the year before. No matter how positive I tried to be, I could not bring myself to be as stoical as Deb.

Maybe it was from watching everything unravel the past four years and all that befell Deb. Maybe it was my fears, concern, and heartbreak for my cousin Sue plaguing me since we last saw her, heaped on top for good measure. Unlike Sue, Deb had at least experienced wondrous medical marvels and miracles. Deb was blessed with a wondrous physician. Yet the medical care for Deb and Sue was connected in a journey filled with chaotic and needless meltdowns, pain, and suffering.

After so many years in the healthcare business, I thought I knew it all about care in America. Through the myriad of things I didn't know and had to learn the hard way, it was difficult to look in the mirror. I didn't know what I didn't know until I learned it, and by then it was too late. We had moved two times and almost moved a third. I changed jobs four times to get the right insurance to be covered at the right place to get the right care and I still failed miserably.

I relive and still feel as lost as I did in the light of the TV screen in our bedroom that evening, listening more intently to Deb's breathing as she lay fast asleep rather than the cheerful onscreen shenanigans nearing the ball drop. I sat lost in solitude and despondency, continually stroking Cody's head as he lay between us. I sat lost in a bottomless round of Crown, staring at the back of Deb's head as the ball dropped. I sat lost of hope for the year ahead. I was not wishing to be prophesying nor foreboding. But I had a very sick feeling in my stomach and hurt in my heart that I just could not shake.

Once More unto the Breach

"January the sixth, two thousand and five."

There are a few days in your life you can remember in such clear, surreal detail. The moment you awoke. The black coffee you poured. Standing in your backyard, watching your dog scurry about as the sunrise barely sprinkled through the trees. Hoping against hope when the sun set, it would all continue to be so beautiful.

Early on the morning of "D-Day," as Deb referred to it, she slowly rolled out of bed and got ready for a very long day. After months of barely speaking about that day of looming consequence and seemingly taking it all in stride, Deb arose uncharacteristically irritable. Not being able to have her cherished coffee was not helping her cranky disposition. Deb was not a big soda drinker, or for that matter water or any other liquid, including alcohol. But coffee, now that was her juice of life. From the very moment she arose until the time she dropped her head on the pillow, pretty much all she drank was strong coffee with two sugars and a little cream.

Over the years, I marveled how she was able to stay so slender drinking that much sugar every day. From sunup to sundown, she always had her "Bunn" working overtime. Thankfully, those coffee makers seemed to always take the proverbial licking and kept on ticking. But nonetheless, Deb still maintained a spare in the pantry—just in case—right next to her stock of Dunkin Donuts coffee. While Deb always teased me we should have had stock in my favorite crab house, I always felt we should have owned a Dunkin Donuts. While Deb would drink any kind of strong coffee, she loved Dunkin Donuts coffee. I frequently made the crosstown donut run, to the delight of our sons as well, go figure.

Even with no coffee flowing in her, we arrived at the lab on the top floor of the medical center main building precisely on schedule for Deb's 8:00 a.m. fasting blood draw. These days it was so much easier for Deb because the phlebotomist could simply use her port-a-cath and did not have to poke and prod around her tiny veins as when her journey started. Her first oncologist refused to allow anyone other than her to access the port that was implanted just above Deb's right breast.

It was fortuitous the blood draw always went so well, because next up, we traveled down floors of silence to report to radiology in preparation for Deb's CT scan. Unlike some of Deb's CT scans, this one was ordered with "contrast," further enhancing the CT images. Prior to being placed inside the CT tube, a contrast dye is delivered intravenously. Sometimes Deb was successful in getting the radiology team to use her port to deliver the iodine-based contrast. This would not be one of those days, further enhancing her unconventional grumpiness that morning, along with her distress at being confined, making scans such as the CT always challenging for her.

Around 11:00 a.m. Deb was called into the back of the radiology department and had the imaging completed in preparation for her next and last appointment of that day with Dr. Elizabeth, at 4:00 p.m. Normally we would go to the cafeteria located on the main floor of the building where imaging and Dr. Elizabeth were located to wait it out.

But Deb decided she wanted to go out for coffee and to try to put something in her stomach. Hers was not the only stomach tied in knots as we both barely picked at what we ordered. The silence was deafening as we sat in a small booth seated across from each other, lost in reflective thoughts. My attempts at small talk were unsuccessful. Even Deb's trademark "gotta-have-coffee" did not sit well with her.

Among the many things we cherished about Dr. Elizabeth, she never seemed to overbook her schedule and she was never rushed during her appointments, no matter how many questions she was peppered with from us. On cue, we were called into the back around 4:00 p.m. Once again, this venerable oncologist would walk into the room and warmly greet us with her wonderful toothy smile and ask how our Christmas and New Year's were.

Given the type of caring and holistic physician she is, Dr. Elizabeth not only queried Deb about how she was doing and feeling but also inquired as well about our sons and asked me how I was doing. Deb did not say a word about her hands, so I did not volunteer my observations. As typical, Dr. Elizabeth's first clinical step was to thoroughly examine Deb. She listened to Deb's heart and abdomen, working her way down to Deb's ankles and then onto her back. She pronounced, looking up at Deb with her stethoscope still in her ears, "Both lungs sound really good. Nice and clear!"

As she had before, Dr. Elizabeth studied the scars on Deb's back when she listened to her lungs from behind. As she examined the two large, round scars on Deb's left hand, I waited to see if she would notice any changes in Deb's fingernails. But she did not say anything. I began to hope I was imagining it all.

As typical, Dr. Elizabeth had already studied the CT scan results taken mere hours before. We were again witnessing the Holy Grail of care, real-time healthcare in action. After a flurry of keystrokes and mouse movements, Dr. Elizabeth displayed the CT images on her large computer screen and immediately turned to us. My heart was racing as I reached for Deb's hand and she gripped it tightly.

"I am sorry! But it does appear that one spot in your right lung is most probably a small cancerous lesion based on what we are seeing from the scans."

Dr. Elizabeth patiently waited for us to absorb the news before turning back to her computer screen. She meticulously panned, rotated, and zoomed the images as she calmly and precisely shared the details of what was occurring inside Deb's battle-worn right lung. When she was done, she asked us what questions we had and then gave us her game plan.

"We need a biopsy to be conclusive, but before you undergo that procedure, I would like to first get another PET on you to make certain we are not seeing anything anywhere else."

Once again, we found ourselves sitting dumbfounded while waiting at the light to leave the medical center in the middle of rush-hour traffic. Suddenly Deb turned to me and made a proclamation.

"We ain't sayin' nothing to nobody until after that biopsy."

I must have remained silent just a touch too long, lost in my "told myself so" doom and gloom because when I looked over, Deb was now giving me her special look. I was so shell-shocked I remember thinking I didn't know what the hell to think or say. Deb was not letting it go, especially because of the difficult discussions we had around Christmas about her decision to not let our mother know what was happening.

"OK?" she stated more firmly, raising her voice and more forcefully asking, "We are in agreement, right?"

We had already kept everything to ourselves, so I nodded in agreement. That is with the exception of the biopsy and not at least telling our sons that their mom had to undergo some procedure that day. I had become as fearful as Deb based on prior experiences that something would go wrong. I wanted to at least give Thomas and Steven a heads-up. I did not want to blindside them if something went wrong.

I decided that was neither the time nor place to have that discussion or any disagreement with Deb, given everything swirling. I found myself once again trying to fathom what Deb was going through on the inside as she sat staring straight ahead, stone-faced on the outside. No one peering into our vehicle that day would have ever guessed the tragic news she just received.

The rest of the drive home was as hauntingly silent as the month to come would be. Except for Deb relenting on at least telling our sons she had an outpatient procedure at the hospital, she completely closed down and did not want to discuss anything related to her scramble of upcoming appointments: her PET scan on Feb 7, the follow-up with Dr. Elizabeth scheduled Feb 9 to review the scan results and make a final go-no-go decision for her biopsy procedure on February 11.

As others would awake with thoughts of commemorating the day of love on February 14, we would arise awaiting the afternoon appointment with destiny anew, good or tragic. The flurry of all Deb’s appointments that week would culminate with an afternoon appointment with Dr. Elizabeth. She would deliver Deb’s biopsy and test results.

Certainly, Dr. Elizabeth would address the “What If” question. But what of that other question I had long feared?

“What Now?”

Knowing what was to come, the belabored conclusion to January 2005 finally gave way to a February that was greeted with the impenetrable silence standing between Deb and me as we arose on the morning of February 7, lost in a million thoughts all centered around one as we made the short elevator ride up one floor to the radiology department for a Positron Emission Tomography or PET scan, as it is more commonly called.

Of all the tests Deb had to undergo, this was the one that she dreaded the most. In a process similar to the CT scan, you are placed on a thin, flat table that is then slid into a cylinder tube. The PET scan takes roughly twice as long as the CT scan. Deb had great difficulty making it through the PET image process even with a sedative. She was usually badly shaken by the procedure.

The PET uses a special dye containing a radioactive tracer, or hot sugar water, as one of the techs referred to it. It is not done often and usually only after other tests have been performed, confirming either the suspicion or the detection of cancer, and when trying to determine where else it may have spread.

While the technology has advanced greatly over the last decade and is now used as a diagnostic tool for other conditions, back in those days, the test results resembled a full-body gray-and-white X-ray. It was conveyed early in Deb's treatment that anywhere a black spot appears may spell trouble—as in cancer trouble. However, as I would learn in later years, that was not entirely accurate. There are certain hotspots that light up as dark black spots because they have a higher metabolic activity, such as the bladder, kidneys, and brain.

Deb's name was called at her appointed time of high noon. She disappeared into the back to first be injected with nuclear particles of destiny. As when undergoing a CT with contrast, sometimes Deb was able to convince the radiology tech to inject the dye into her port. But some techs did not like using the port and insisted on doing things the old-fashioned way. Again, this would be another one of those occasions. So the PET procedure, as had her last CT, started out in a bad way for Deb.

Once slowly injected, the special dye takes an hour to be absorbed in the body before the scan that also takes roughly an hour to complete can begin. Combined with the pre- and post-PET procedures and setup, Deb slowly emerged from the back almost three hours later. Deb complained about the CT scan she had weeks before because the complications from all of the lung surgeries had made it difficult for her to lie back or move in certain positions. On the way home, I clearly heard as Deb sobbed and shared, the PET was far worse this time and not just in terms of claustrophobia, but also, Deb's extreme physical discomfort because of the cumulative impact of all the procedures she had undergone.

The appointment with Dr. Elizabeth on February 9 came with mixed blessings. She once again displayed Deb's images on the screen and again explained the results in very careful detail. The good news was that there were no potential cancerous areas visible from the PET scan anywhere in Deb's body. The bad news was we had even more evidence of the need for the biopsy procedure scheduled for the 11th on that one small tumor in the upper quadrant of her right lung.

Right Where We Started

Now you are caught up to where I began Deb's journey, now many pages ago. I started and then left you hanging on the news of Deb having another biopsy procedure on Feb 11, 2005. That procedure had gone so much better in execution than her first biopsy in early January 2001. The one that begat the initial battles that led to a long war. War not just with the disease cancer, but also as well the other disease: the great confusion, complexity, and cost that is, "Healthcare in America." As tragically symbolic, Deb was still unable to escape the battlefield without any collateral damage even while the biopsy procedure went well. Once again, Deb had been handed a prescription for the very medication she was allergic to while wearing an allergy bracelet in the same name as her deadly allergy. Morphine!

Romantic Valentine's days were a far distant memory, but I still tried to make the day of love be shown and felt that way. From the time Deb awoke on Feb 14, however, she was silently lost in her coffee, not wanting to go out for lunch before her appointment that afternoon with Dr. Elizabeth as I tried to get her to do. She also proclaimed we would be doing whatever at home for dinner that evening as any day. Nothing special.

It was a sad day as mere days before, Deb had already been preliminarily diagnosed based on the PET. The biopsy she just had was a potentially dangerous step that needed to be checked off the list. The truth was, both Deb and I already knew the truth. The only thing to ponder now was options for the most effective way to cast out this new horde of alien invaders from her body. How is this new set of entrants onto an old battlefield going to be expelled before they can quickly multiply?

As so many times before, Dr. Elizabeth would explain the results of the biopsy as she displayed them on the monitor in the room. She carefully presented and explained the discussions and planning with her many other colleagues, other specialists involved in the departmental meetings to analyze Deb's case.

Of the options given Deb, her doctors felt she should undergo a new procedure called a Radiofrequency Ablation (RFA) because of the delicate location of the new tumor. As with the original tumors, this one was also within and around a critical cluster of nerves in her right shoulder. While rarely performed in the lung on a tumor of such shape and location, it seemed the best option, as recommended by her surgeons. Hell, it was the only option, especially given the complexity and risks associated with the alternatives. As this was the only tumor the battery of tests and scans revealed, it made sense to aggressively treat this new invader. In many ways, we were fortunate to be at a facility that offered such an option and bestowed such a chance at life. Yet there were risks.

At first, things did not appear so grave. Her prognosis was not so dire. Deb only had one small tumor in her right lung. As my wife was making the decision among available treatment options, she was comforted by the fact that was the only place cancer existed in her body. The heartbreaking irony was not lost on either of us. This was the exact same location where her painful journey began so many years before.

We were forewarned about the complications of the procedure, most of which Deb ended up with, including nerve damage. While her case was not the ideal situation to perform an RFA, Deb's surgeon felt this was the best course of treatment and would lead to getting rid of the tumor with no lung resectioning procedure. Most importantly, no chemo that Deb could no longer tolerate, or, for that matter, other follow-up treatments. Deb bravely consented to go through the procedure. She was scared to death to undergo another inpatient procedure at their hospital facility, but Deb was also scared to death not to. Again, we sat at the light waiting to exit the medical center, looking at each other, lost in a seemingly inescapable dark tunnel.

"I'll do any damn thing I have to if they can quickly get rid of that damn tumor," Deb very emotionally blurted out on the way home.

The RFA procedure Deb would have a week later based on the biopsy and tests would go as well as it could. But Deb would again live many of the reasons a year before she had vowed through her pain and suffering to never return. As soon as Deb arrived in her room on the top floor of the hospital, she asked for something for her upset stomach and increasing pain.

After spending ten grueling hours at the hospital and with no food or water or normal medications since the day before, this should have been understandable. But Deb was told that they had to wait and get orders from her doctor. The promises and understanding that existed floors below in recovery that they would immediately take care of Deb when she got up on the floor, was now lost during the ride up the elevator.

Two hours later, when Deb again inquired about the pain control, we were devastated to be told once more, THEY COULD NOT

LOCATE HER RECORDS. But as soon as they could, things would proceed quickly. More was lost in the elevator than understanding, it seems.

But as we noticed there were no signs in Deb's room warning others, we inquired, as we were warned to always do, about the MRSA quarantine procedures that Deb had been given the year before. The floor nurse flatly told us that the hospital, "did not give you that. You gave it to yourself. That is how it is spread. Unless it is active, no special precautions are needed," she coldly and wrongly stated before walking off.

Initially, we were happy to see the doctor Deb had only recently and briefly met in recovery. He had told Deb through her haze that he would be her admitting physician during her stay. This was not the physician who had performed the procedure, nor any doctor Deb knew or who knew of her medical history. Nonetheless, after having spent only a few minutes at most with Deb in the recovery room, the new doctor now spent even less time at her bedside.

With his one foot already out the door, my wife tried to quickly explain her pain control challenges from all the procedures she had endured. While Deb was made comfortable in recovery, the pain was starting to worsen. As always, which was why Deb was always a nurse favorite, she was polite and tried to bring a smile to those around her no matter how bad she felt inside or what was going on in her world. However, it was obvious as the doctor interrupted her, "Deb had already been labeled."

All this physician heard was that Deb still needed to take a daily dose of pain medication and she seemed to know a lot about drugs. He never asked Deb why. He never considered the procedure Deb had that day. He never looked at the deformed crater in her side from the stay at the facility the year before. The site of a chest tube that impaled her for over five weeks as it became infected and almost cost us her life. When the MRSA blood infection she had been given led to more complications, repeated lung collapses, and three more surgeries. This doctor never even mentioned Deb's MRSA or why there was no quarantine procedures in place.

He never looked at the severe scarring or disfigurement. He never reflected on the nerve damage, especially of the tender area in Deb's side that was quickly and sloppily cut away in the middle of the night by a colleague a year before with no anesthetics. The source of why Deb needed that mild daily dose in the first place. All of this in addition to the pain Deb would live with for the rest of her life with constant numbness and tightness in her chest and back, unable to wear anything close fitting—unable to be touched or closely held.

I clearly heard what this doctor and nurse thought of Deb as I walked up to the nurses' station to return the menus I had been given for the local restaurants. By the time Deb was finally "cleared" and told she could have something to eat, we had missed the hospital dinnertime. It was now up to me to feed her.

In the room off to the side of the nurses' station, I could clearly hear the doctor who just left my wife's room having spent so little time with her. At the desk, he took plenty of time to talk with the nurse he was with about the patient who did not have a frown on her face or seem to be in pain. The patient whom he ordered would receive no extra pain medication, as he would write in her chart and as we would learn just a couple hours later. I was so damn enraged and angry standing there listening to them talk. But I knew I had to calm down and keep focused on the mission at hand. Blowing up at the nurses' station and yelling and screaming and getting kicked out of there would not best serve my wife or allow me to remain in her room standing guard over her all night.

But had I known he actually translated his thoughts into orders, I would have even at risk of not furthering our cause for appropriate care, jumped across that desk and confronted them on the spot. They had the time to bemoan just another "druggy" patient. But they did not have the time to really look at her history, not just clearly documented at that facility, but caused by it. They did not even have the time, as we also found out the next day, to write the orders so that others would allow Deb to get something to eat. But the doctor did find the time to write an order damning Deb to a world of pain all night.

As we have so often experienced, the healthcare wind unpredictably changes fast. Several hours later, as quickly as that nurse and doctor blew into and out of our life, or at least off shift, a wonderful, caring, and kind nurse entered. She confirmed to us that she was under orders not to increase or change my wife's medication.

She nonetheless promised she would do her best to make Deb comfortable through the night. She kept her word. Her care was wonderful that night. But it could not overcome being fed so late that Deb at that point could not hold anything down. No care the nurse could muster, however, would lessen Deb's severe pain through the night.

The next day we were again fortunate to be touched by other angels. The day nurse, who was new to the facility, became just as frustrated as Deb was in the delay in getting her something to eat. She diligently tried to stem the delay in getting Deb onto oral medications because the same doctor who had condemned Deb to pain had not even taken the time to write the orders needed when Deb was admitted to the floor.

Deb's heaven-sent nurse then succeeded in getting a pain management specialist to see Deb. We were so fortunate to finally have one assigned to her case who could quickly intercede in her care. The doctor could only shake his head as he was told of the events from the night before. It was obvious that he had taken the time "before" he even walked into her room to become familiar with Deb's case. He explained to us why the Radiofrequency Ablation procedure Deb just had on her tumor was so painful.

"It is like having a red-hot poker stuck through your shoulder and into your lung! There is a good reason," he told Deb, "you are and will be in pain for some time to come."

But he promised he would work with Deb and do all in his power to make sure the events of the night before were not replayed during the rest of her hospital stay. He took the time to ask Deb about the pain she was having before the recent procedure. He took the time to examine all of her scars and studied carefully the new "collateral damage," as the physician who had just performed the procedure termed it. Numbness in Deb's shoulder and arm to go with that she would forever have across her chest and back from previous procedures, and a droopy right eyelid that we did not know at the time would never subside and become heart-wrenchingly permanent.

Shortly thereafter, an Infectious Disease nurse came into the room and told us that they had missed the fact that Deb had a recent case of MRSA. She asked if we were familiar with the quarantine procedures as she started to hang up the warning signs on Deb's door. She ordered the day nurse to glove and gown as soon as she walked in the room, and to no longer use her stethoscope. Anything touching my wife had to be discarded. A new stethoscope was hung next to the bed that would be disposed of and could not be removed or reused.

When I shared that we not only knew the protocol but also had strongly inquired about it the night before, the nurse became visibly upset. Actually, she was downright pissed off. As I asked her to explain how my wife could have given herself MRSA, the nurse softly said, "That simply is just not true, ma'am. You did not just give yourself MRSA." Continuing to apologize profusely for what was said to us, she said, "You just keep doing what you're doing—both of you! You are absolutely doing the right thing. Thank you."

When the pain management doctor came back later and saw the quarantine warnings, he blew a gasket. He had used his own stethoscope and while he washed his hands before and after seeing Deb, he had not worn gloves during my wife's earlier examination. He commanded the patient care technician (PCT) to immediately get my wife's nurse. When she arrived, the visibly angry doctor walked out of the room, but we could still hear them in the hall. He demanded to know why he was not informed prior to treating Deb.

"Why the hell wasn't her MRSA one of the first things in her chart and on her door?"

Any thought we had that nothing could top that conversation was quickly vanquished hours later as we capped off that hospital stay with another message to call Patient Accounting. Given I knew we were now out of network at the hospital, I nervously called back with great concern that a new financial snafu was again brewing that would complicate Deb's discharge.

Instead, I heard once again what we had back in May. After well over a year of trying to collect from our insurance we had during Deb's one-week stay that turned into an almost three-month nightmare, both the hospital and medical center were giving up again. While we made tremendous progress in reducing our bill, both the hospital and clinic felt at this point they had gotten all they were going to get and it was time to come after us for the balance of what was due. Never mind that what befell Deb was not in any way her fault or anything we could have controlled or prepared for.

STATEMENT NUMBER: 1983384
P/C L

SHOW AMOUNT PAID HERE $ ____________

OFFICE PHONE NUMBER [redacted]
CLOSING DATE ❶ 03/06/04
GUARANTOR NUMBER [redacted]
PAGE NO. 01
NEW BALANCE 16,261.59

WALTER CULBERTSON
[redacted]

[redacted] CLINIC [redacted]

NOTE: Charges and payments not appearing on this statement will appear on next month's statement.

000000314[redacted]

CHARGES APPEARING ON THIS STATEMENT ARE NOT INCLUDED ON ANY HOSPITAL BILL OR STATEMENT

DATE OF SERVICE	PHYSICIAN	DESCRIPTION	BILLED TO INSURANCE	PATIENT RESPONSIBILITY
		Previous Balance	13021.78	16261.59
		DEBORAH CULBERTSON 5536-670-2		
	[redacted] CLINIC [redacted]			
030104	0001	Payment(s) PRIMARY INSURANCE PAYMENT	187.17-	
		Insurance Balance	❷ 12834.61	

STATEMENT CLOSING DATE: 03/06/04 PLEASE INDICATE YOUR GUARANTOR NUMBER WHEN CALLING OUR OFFICE: [redacted]

BALANCE FORWARD	PAYMENTS	CREDITS	CHARGES	BALANCE OVER 30 DAYS	BALANCE OVER 60 DAYS	BALANCE OVER 90 DAYS	NEW BALANCE PAY THIS AMOUNT
16,261.59							❶ 16,261.59

***Learning Opportunity**: ❶ Seven months after Deb's initial lung procedure, we already owed the medical center clinic $16,261.59. ❷ They were still battling the insurance company for $12,834.61. ❸ Just two months later, the medical center gave up on our insurance and literally, overnight, added their balance due to our bill!*

STATEMENT NUMBER: 2110454
P/C L

SHOW AMOUNT PAID HERE $ ____________

OFFICE PHONE NUMBER [redacted]
CLOSING DATE ❸ 05/29/04
GUARANTOR NUMBER [redacted]
PAGE NO. 01
NEW BALANCE PAY THIS AMOUNT 26,473.84

WALTER CULBERTSON
[redacted]

[redacted] CLINIC [redacted]

NOTE: Charges and payments not appearing on this statement will appear on next month's statement.

00000031[redacted]

CHARGES APPEARING ON THIS STATEMENT ARE NOT INCLUDED ON ANY HOSPITAL BILL OR STATEMENT

DATE	PROVIDER	DESCRIPTION	BILLED TO INSURANCE	PATIENT RESPONSIBILITY
		Previous Balance	-201.22	26773.84
		Applied to Guarantor		
	[redacted] CLINIC [redacted]			
051404		Payment(s) PERSONAL PAYMENT-TAMPA		-300.00
		Insurance Balance	❸ -201.22	

STATEMENT CLOSING DATE: 05/29/04 PLEASE INDICATE YOUR GUARANTOR NUMBER WHEN CALLING OUR OFFICE: [redacted]

BALANCE FORWARD	PAYMENTS	CREDITS	CHARGES	NEW BALANCE PAY THIS AMOUNT
26,773.84	-300.00			❸ 26,473.84

Staring at my wife again in a hospital bed, again being ripped apart by the process, the system, and her pain, my mind was spinning out of control, given everything that had and was whirling all about us. I was being told on the other end of the phone that we must increase our monthly payment to at least $2,200 a month, on top of the $1,100 we were also paying to maintain our COBRA health insurance. Given all our other out-of-pocket costs, we were now confronted with a monthly outlay for our healthcare of easily $4,000 a month or $48,000-plus a year.

As we were leaving, Deb pronounced, "NEVER AGAIN!"

Once more at home in her own bed, Deb's attention alternated between battling her pain and shoulder numbness and splattering her Cody-bear with affection. But it was immediately clear the RFA procedure was to have more traumatic impacts than we had been forewarned about. Deb barely moved from the bed and did not even attempt to maneuver into her cherished spot in the front room. Despite her vows to never return, it seems "never" always comes. Within a day after Deb was discharged, she started running into more complications. We found ourselves again on the phone and then headed over to the office of her masterful oncologist, Dr. Elizabeth. That drive was one of the longest rides of my life. Deb just silently stared out the window all the way over.

Dr. Elizabeth was at this point the only doctor that Deb had any faith and trust in. On the way over, Deb had already made the decision that despite her increasing pain, shortness of breath, and a temperature that had reached over 102 during the night, she would not be admitted.

"I ain't ever going back to that fucking hospital again."

Dr. Elizabeth ordered an immediate CT scan and other tests. As we were again led back to her office a few hours later, Dr. Elizabeth was working the phone calling other colleagues, validating the best care she could give to combat one of those small little risks associated with a procedure. Side effects that always seemed to happen to Deb, in this case, pneumonia in the lung and surgical site now confirmed by the CT scans. I can't help but wonder how those risks are initially calculated and if or how they are updated over time based on "actual" patient and clinical experiences.

During the "real-time" consultations, it was clear the doctors had little familiarity with the new RFA procedure Deb had performed in her lung. Calmly and with careful thought, Dr. Elizabeth quickly dissected all the information and determined the best way to treat her pneumonia. She wrote a series of scripts and gave us her best marching orders.

Life in the Fast Lane

Watching Dr. Elizabeth in action years after she had first given us her home phone number, there was no doubt we had made the right decision not to leave the care of this most remarkable person and physician. No matter what it would forever cost, even if it turned out to cost everything.

Over the next week, while Deb's lungs appeared to sound clearer, she started to develop other challenges. But she was nonetheless determined no matter what to be seated next to me in the arena jamming to our favorite group, the Eagles.

Despite my trying to talk Deb out of going, amazingly, incredibly, and any other superhero adjectives I could insert here, less than two weeks after undergoing the RFA procedure, and getting pneumonia and still in great discomfort, there she was. Superwoman was climbing a series of stairs up to our seats at the arena with two friends, Mike and Betty. Deb could not move around a great deal and was not jumping up and down or waving her arms around like everyone else. But there was no one in that arena or an Eagles fan anywhere, for that matter, who ever glowed so brightly, finally listening to <u>our band</u> live, together!

In addition to all the other factors that drew us together, Deb and I had a very similar music genre and for both of us, one group stood above all. As a kid, the Eagles were the first live performance I ever attended, in 1972. From that first concert at that outdoor concert hall in the middle of a preserve in Columbia, Maryland, no one else I ever saw compared. I traveled to Athens in '73 to see the Eagles again with some of my Ohio cousins, and again the following spring in D.C. in '74.

Deb had an equally impressive list of times that she had seen them perform during what we joked were our, "wild and carefree days." But for both of us, 1975 brought about many adult changes and going to concerts was not a priority. I headed off to the Navy after graduating from high school. Younger than me, Deb was getting married and having her first son, Ray.

But in the early summer of ’83, the Eagles would emerge back into both of our lives in the most magical of all ways on our very first date. After closing down the restaurant, we were lying on the beach after dinner on lounge chairs we had pushed together from one of the local hotels. As we talked and talked against the backdrop of waves hitting the shore, I was alternating glances between the stars in the sky and the stars in the eyes of the beauty next to me. I lay back, looked up to the sky and the heaven above and simply stated what I was feeling.

“I got a peaceful, easy feelin'!”

At that Deb rolled over onto my lounger, half on top of me, staring straight down into my eyes and sang the next refrain:

“And I know you won't let me down!”

What followed was our first and what felt as if one of the longest kisses in my life. In a magical, transcendental moment, that forever became our song. Over those summer months, we cruised all over the beach with the T-tops popped on my ’79 blue Corvette. We continuously blared the “Eagle Live Volumes 1 and 2.” Everyone in the vicinity of that Vette had little doubt about who our favorite group was, whether they liked it or not!

Twenty-two years later, not even two weeks after undergoing an advanced surgical procedure, and after four years of enduring hell, I was still looking at stars in those gorgeous blue eyes. Deb was as radiant as ever as we attended our first Eagles concert together after all those years and that first kiss. Over the decade the band had been back together, we talked many times about trying to see the Eagles. But those desires gave way to so many other priorities and responsibilities during those years.

Throughout the performance, I kept my eyes on Deb, making certain that she was OK. I was not surprised, given her strength and moxie, that she was able to sit for all those hours and fight away the pain I knew was raging through her body. We had arrived very early so Deb would have plenty of time to slowly make her way from the handicap parking area to our seats. After the Eagles performed about two dozen songs, they concluded with “Life in the Fast Lane” and left the stage.

We had already decided before arriving that we would leave before any encores started so that we would be able to get out of the arena without being trampled upon or having Deb in pain sitting for hours in traffic with everyone else trying to exit. While everyone stood and screamed for an encore, Deb gave the sign it was time to leave, pointing to the aisle.

As we tried to make our way down the row to the aisle, those around us could see that Deb was now in a little distress. Everyone graciously helped Deb by making certain she had enough space between seats to be able to move down the row. Our plan worked like a charm as we were able to get out of the arena over to our car and out of downtown with no delays. But Deb paid a painful price for our evening finally seeing together the group that we both dearly loved. Her back, shoulder, and her neck were hurting badly and she was in great discomfort.

Yet, the very first time I dared to utter, "we should not have gone," Deb immediately shut me down.

"That's bullshit. There was no damn way we were missing seeing them. No doctor or nothin' they could do to me would ever stop that."

From our first days together, we had made a promise to each other, and a pact. "No matter the argument or disagreement, or what was happening in our lives, good, bad, or ugly, no matter what, we would never go to bed without a goodnight kiss."

That evening as I happily delivered again on that decades-old promise, Deb reached up and put a hand on each side of my face. Through now her tears, she lightly kissed me repeatedly. She then sang to me a modified version of what she had the night of our first kiss.

"And you never did let me down."

Lord knows I was doing all that I could to never let her down. While Deb drifted off to a restless sleep that evening, as typical, my brain had not shut off and was a flurry of mind-numbing minutia. Replaying the events of that evening and marveling over how Deb did it all. Recalling and burning to memory the look on Deb's beaming face and her great joy shining down on the stage of our favorite musicians playing our favorite music. But she paid dearly for it. I watched her toss and turn, witnessing her struggle and listening to her moaning in her sleep throughout another long night.

The next day Deb awoke in even more pain, and over the days that followed, the numbness in her shoulder and arm continued and became more pronounced. She felt tingling and burning mostly in her right hand but at times in both hands unrelated to anything to do with HOA. About a week after the concert, Deb dropped a cup of hot coffee on herself after a sudden loss of strength in her right wrist. Deb appeared to increasingly have far less strength in her right hand than before the RFA.

Of all the side effects from the RFA surgery, the pain, the numbness, and the burning, the complication that was most damming and so broke Deb's heart was the now-significant drooping of her right eyelid. I was working in my office when I heard a loud crash from our bedroom. I ran from my office fearing the worst, that Deb had somehow fallen. I instead found Deb seated on the side of our bed with her hands covering her face, sobbing. Cody was on the bed standing over her.

Rushing through the bedroom door, I started to ask her, "What's wrong, Babe? What happened?"

But Deb abruptly stopped me in my tracks when she hollered at me, pointing to the floor, "Don't take another damn step! Glass! Don't step on the glass."

Deb's glass hand mirror was in hundreds of pieces from the middle of the room over to the wall, which had a large dent in the drywall. The pink glass mirror handle and frame were broken in several large chunks also strewn about the floor.

"I'm a fucking hideous monster," she kept saying, now covering her right eye with her hand. "I should have never done it. I should have never let them operate on me again. I would have been better off if I had just let the damn thing grow inside me until it killed my ass."

Deb again vowed to never return to the hospital. No words I could muster would console her as I slowly cleaned up the glass while she lay back in bed wrapping her arms tightly around Cody, who never left her side and now curled up next to her. I sat on the edge of the bed for the longest time petting Cody and lightly stroking Deb's shoulder, trying again to comfort her. Finally, in seeing that was not possible, I maneuvered next to Deb and Cody and curled up, holding Deb as she cried herself to sleep.

A few weeks later, on an early Saturday morning, I was fortunate that Deb would once again break her promise to never go back. During the weeks since the lung procedure, her condition continued to spiral downward. Deb was so ill she could no longer get out of bed. Deb could not even open her eyes without the room spinning around her.

I had begged, pleaded, and tried for hours, but even as the room was now spinning wildly out of control as she lay in bed, Deb refused to allow me to call 911 or let me call Dr. Elizabeth at home. At that point, I didn't care, and against Deb's wishes, I walked into the other room, more grateful than ever this extraordinary doctor so kindly provided us with her personal number. On that Saturday morning, as I called Dr. Elizabeth, I was never so thankful for anything as when she picked up on the other end.

"What's happening, Walt? Is everything OK with Debbie?"

As I shared what was transpiring, Dr. Elizabeth calmly asked me to put Deb on the phone. When I walked into the bedroom and handed the phone to Deb, at first, she was not at all happy with me. I had done exactly what she had asked me not to do. They talked for about fifteen minutes and I could tell Dr. Elizabeth had successfully ridden against the tide. I was so grateful that Deb's physician angel was able to convince Deb to go back to the hospital in that phone call.

A short time later, I would again meet the paramedics at our front door. The local EMTs had most distressingly become the most frequent guests to our home over the past couple of years. They arrived once again fully prepared to do battle with the alcove entrance to our bedroom door. Getting Deb out of there was indeed a challenging task. But the now "bedroom-door-experienced" EMTs came armed this time. They very carefully moved Deb out of bed onto a new type of stretcher. While it seemed to me to be smaller and less sturdy, according to the paramedics it was greatly improved over the older generation of heavier stretchers. It certainly seemed more flexible and maneuverable as they more easily got Deb out.

Deb and I had talked and planned for weeks to get her to another local facility that many of our friends and some colleagues spoke highly of, that I verified was in network and accepted by our insurance. Knowing that this day was quickly coming based on Deb's condition, I made every attempt to get recent copies of her medical records so that we could be ready.

However, the part of HIPAA that is supposed to allow "we the patients" to get copies of our health records, did not work as well as I had expected. I will never forget standing in the hospital medical records office being told that because of the HIPAA legislation and the size of my wife's medical records, it would cost well over $3,000 to obtain a single copy of her medical records. At a dollar a page, plus handling and applicable taxes, I had to settle for just 199 pages and a $219.08 bill.

INVOICE

Smart Document [redacted]
P.O. Box [redacted]
[redacted]
Fed Tax ID [redacted]

Invoice #: 0026261550
Date: 03/12/2005

Ship to:
DEBORAH CULBERTSON
[redacted]

Bill to:
DEBORAH CULBERTSON
[redacted]

Records from:
[redacted] HOSPITAL
[redacted]

Requested By: DEBORAH CULBERTSON
Patient Name: CULBERTSON DEBORAH R
SSN: *** ** ****
DOB: 081757

Description	Quantity	Unit Price	Amount
Basic Fee			0.00
Retrieval Fee			0.00
Per Page Copy (Paper) 1	199 ❶	1.00	199.00
Shipping/Handling			5.75
Subtotal			204.75
Sales Tax			14.33
Invoice Total			219.08
Balance Due			219.08

Pay your invoice online at www.[redacted].com

Terms: Net 30 days

Please remit this amount : $ 219.08

Learning Opportunity**:** ❶ *Despite the fact that HIPAA only allows providers to charge "reasonable fees" for patients to obtain copies of our health records, many states have passed laws that allow doctors authority to charge a dollar a page. Clearly, a $219 bill to obtain just 199 pages of your record is not "reasonable!"*

On that Saturday, however, with or without those records, Dr. Elizabeth confirmed to both Debbie and me over the phone what we already knew. My wife's care was too complex and advanced to even begin to try to start anew at another facility. Promising Deb she would meet her at the emergency room and stay her angel looking over the shoulder of her colleagues, was the only thing that got Deb to agree to be rushed back to the hospital, rather than die in her bed, as she had requested of me that morning. The end of March 2005, I was once again trailing the ambulance back to the place where Deb was terrified to go, but as so many times before, she had no choice.

Spinning out of Control

Spending the entire Saturday on her weekend off, Dr. Elizabeth stayed with her patient, feverishly working to try to determine why the procedure performed a month earlier could cause the worsening condition she was witnessing. As Saturday evening came, there were still no answers. Finally, at the end of an extremely long day for all, Dr. Elizabeth returned home to her family. In an unfortunately all-too-familiar routine, I made my bed in the chair next to Deb's side, so grateful that my friend Mr. Bill once again came to our rescue and was checking in on our sons.

Early the next morning the real extent of what was happening would start to be tragically revealed. As I tried to help Deb get from her bed over to the bathroom, she lost all use of the lower part of her body. All I could do as she started to hit the floor was to push her back toward her bed.

As Dr. Elizabeth was at church or home with her family, I was with a wonderful team of nurses trying to get my wife cleaned up and back into the bed as she was soaked from the original purpose of having to get out of bed to start with. Given Deb's fears about returning, I will never forget the kindness and care given my wife from the moment she arrived on that visit. I will never be able to thank Dr. Elizabeth enough. I will never forget those nurses, Amy, Christine, Marti, and Phyllis.

On a hunch, Dr. Elizabeth ordered a CT and brain scan even before leaving to come back to the hospital that morning. Just after the nurses got Deb in bed and comfortable, she would be whisked away, and those procedures occurred shortly thereafter. I remember being amazed they were doing all that on a Sunday morning.

After hearing the results over the phone from her colleague reading the report, Dr. Elizabeth rushed back to the hospital and up the five flights of stairs, not even wanting to wait for the slow hospital elevators. Her hunch turned out to be tragically clairvoyant. Dr. Elizabeth stood by Deb's bedside as she held Deb's and her mother's hands. Jeanne had herself rushed back into town that morning upon hearing that her daughter was again back to the hospital the previous day.

The news we would receive regarding the real cause of Deb's worsening condition would be the worst of any we had or could have ever hoped to never hear. Deb's journey was filled with so many twists and turns. We went to the breech and back again—time and time again—only to arrive at this most dreadful destination. My mind had already been spinning over the journey we had been on and how we arrived here. But now, with this news, I became sick to my stomach and weak-kneed. I could not fathom how and where we would travel next when Dr. Elizabeth started with those two words.

"I'm Sorry!"

Standing by Deb's bedside, Dr. Elizabeth told us the reasons for her declining condition and worsening vertigo and dizziness. Deb had three tumors that had been developing in the back of her brain that all her scans had somehow missed. On her left side, there were two tumors. One was the size of a marble and another the size of a pea. But the tumor causing all the tribulations was on the right side of her brain near the stem. That tumor was the size of a golf ball and in a very crucial area that controls many critical bodily functions including the circulation of the brain fluid. The tumor was causing great swelling and pressing on that critical area.

Had the cancer been found earlier, in addition to perhaps a better outcome, Deb most probably would have never been allowed to undergo the painful radiofrequency ablation (RFA) she had in her right lung. Every day watching Deb struggle with grievous pain and debilitating side effects from that procedure, I wish we would have known somehow what we seemingly did not. Now my soon-to-be-wife of twenty years and mate for twenty-three faced a battle far worse than any encountered thus far in this war.

Immediately that afternoon, the radiology department at the main medical center where Dr. Elizabeth worked was called into action. Located back at the medical center, Deb was taken from the hospital by ambulance to the radiology facility for an immediate emergency brain radiation procedure. This and a massive dose of steroids saved the day. Until Deb was discharged over a week later, she would be ferried by ambulance each day for more brain radiation. It was an exceedingly difficult process Deb found horrifying.

Once Deb was discharged, I would take her to the facility daily to complete the rest of the treatments. For the radiation procedure, a mask is initially made and then for each treatment placed over Deb's head and face. It is so tight she could not even move her lips or blink. The mask is bolted to a metal table in the radiation room. Deb's arms and legs were also strapped down tightly to the table. Given her claustrophobia, Deb had found being placed inside the CT tube challenging, but this was a whole new level of horrific for Deb.

Even given medication to relax her, the process was petrifying for Deb. That was the closest I had seen up to that point of Deb just giving up after the first procedure. The ambulance crews always did their best, especially on the way back to the hospital when Deb would be reduced to tears and badly shaken with each radiation treatment. On the first few trips back and forth, I convinced the EMTs to allow me to ride in the back with Deb, admittedly against the rules.

It was with the saddest of ironies, on that very day I was scheduled to speak at a medical conference full of radiology oncologists. I was instead coming back from a visit with some of their colleagues who fortunately were not attending the Annual Conference of the Southern Association of Therapeutic Radiation Oncology (SATRO).

Instead of delivering the opening address to hundreds of radiology oncologists, I instead found myself once again trapped in my own Twilight Zone and parallel universe. Rather than preaching about and commemorating the start of enforcement for the HIPAA Security final rule with another of my physician outreach efforts, I was instead returning from a visit with the very medical specialty I was scheduled to speak before at the conference.

Watching Deb bouncing down the highway on that stretcher was more than symbolic of the rocky road I knew would be ahead. I decided there in the back of that ambulance it was time for me to step down from all of my healthcare and HIPAA industry leadership roles. I had many good co-chairs across those groups who had in many ways over the previous months, taken over many of the workgroup responsibilities. Looking down at Deb, I knew it was time to turn over the reins.

But in another legislative regard, another horror would abruptly unfold. For the second time in six weeks, I sat by my wife's hospital bed hoping that in her sleep she was for the moment free from the pain and the nightmare, five days after fighting so valiantly to keep from returning to the hospital for all the wrong reasons. Watching as Representative Sensenbrenner told those listening, including my now-awake wife, we were urban legends.

With tears streaming down Deb's face, we watched the most horrifying reality TV show on the air—C-SPAN. As we watched the hearing on the then so-called "bankruptcy reforms," we clearly heard that Americans like us, in distress over their care that went wrong and exorbitant medical bills, were a myth that simply did not happen in America. So there was no need to be concerned about any unintended "side effects" from the legislation. Certainly not Americans like us, those with insurance struggling to keep from going broke over medical bills. We did not matter.

In pushing for and passing legislation, the images conjured up were of gamblers, impulsive shoppers, and deadbeat dads. Metaphors equated to justification from special interests, not the private images of the father of four working at a job with no insurance. The mother of two, working two jobs who has no choice but to reach for that credit card, even with exorbitant no-insurance cash prices, or deductibles into the thousands, because it is the only means to obtain care for her sick child.

After restraining a great need to put her bedside phone through the TV face of the honorable sir, Deb was now focused on damage control, the talk she was already trying to have with me since our

$4,000-a-month wakeup call. For the rest of the afternoon, as she had the last time she lay in that bed, my wife flatly told me that as soon as she was discharged and able, “I am going to divorce you. I ain’t going to let what happened to my sisters and Ma happen to you and my boys. As soon as my ass is out of here, I’m going to a lawyer.”

She could not bear to see me or our sons live through what she and her sisters did when her dad died of the same disease and lived through the same care and social and medical progression over thirty years before. Deb was exactly the age of our sons when her own family tragedy occurred and she lost her father. Deb had been increasingly haunted by her childhood during her own battle and events of the past five years. She was determined not to allow me to spend the rest of my life, or mortgage our sons’ future, paying off her medical bills.

From that moment forward, Deb begged and pleaded with me to run down and file bankruptcy while I still could before any new legislation took effect. Deb was also concerned about our friends Mike and Betty. Over the course of only months, we watched as Mike, also self-employed, had his care mushroom into almost $250,000 in medical bills through an auto accident, not his fault, a collision caused by a driver with no insurance.

After five years of hell and pain, death sentences and miracles, only five days since being told of having brain cancer, these were Deb’s worries. Instead of gearing up for the fight of her life, all Deb could talk about was divorcing me so that she could become some pauper or ward of the state. So this is Healthcare in America. This is how the greatest country to grace the planet allows its citizens to be treated. We had better wake up and get a second opinion.

After a week of daily and expensive ambulance round trips between the hospital and the medical center, as ambulance services are almost never in network, Deb was discharged the first week of April 2005, to continue her radiation therapy from home. For the next three weeks, I would become Deb’s ambulance. Having not lost her hair during any of her chemo treatments, we had noticed after a week of the first round of radiation while in the hospital, Deb was starting to slowly lose some of her hair. After she started radiation, even though Deb would only carefully run her comb through her hair, more of it came out each day. Once Deb was discharged, she decided to immediately take the advice of one of the radiation therapists to cut her hair short to help decrease the impact of her hair loss when it occurred. She also started to use a soft-bristle brush and a mild shampoo and let her hair air dry and tried to minimize the use of a towel.

As the cumulative physical impacts from all Deb had undergone were already taking their toll, the possibility of losing her hair was almost the final straw. With the exception of the pronounced drooping of her right eyelid, Deb's focus was not as much on the pain or scars riddling her body and the collateral damage from the radiofrequency ablation (RFA) procedure. Her chief concerns now centered on keeping her hair and trying to endure fifteen more radiation procedures wearing that mask wrapped tightly about her face. She was terrified of having her head locked down onto a table that she herself was strapped to, unable to barely move a muscle.

On one side of the coin, Deb was relieved by the decision of her team of radiologists managing her therapy to do more treatments at a lower radiation dose per session. This would have the side benefit of minimizing the impacts of absorbing higher doses of radiation more quickly—one of the reasons Deb was hopeful that she would not completely lose her hair. But the flip side was she had to endure a procedure she found horrifically terrifying and was badly shaken after every episode.

Over the three weeks of daily commutes to the medical center radiology department, Deb became even more petrified and fearful. For the rest of the month of April, Monday through Friday at 1:15 p.m., Deb underwent radiation therapy. The anti-anxiety medication seemed to help some, especially when the dose was increased, but after each treatment, Deb emerged from the back in tears.

The radiology team was incredibly patient, kind, and caring. During each session, they did everything within their power to help make Deb as comfortable as possible. Many went above and beyond the call of duty. We were eternally grateful and Deb always made certain the staff knew it. Still, several times, especially during the last week of treatment, Deb would proclaim she had enough.

"I ain't going to do that shit again. I just can't."

Once home, however, with her Cody-bear on one side of her, and her coffee on the other, Deb would regroup and the next day, make a go at it once again. The Saturday after her last radiation treatment, Superwoman was up and flying around the house once more. Deb's strength and determination were the likes of which I have never seen and may never again in my lifetime. The smile she wore that weekend will forever be a treasured memory, given the road she had just traveled and the rest of the journey that lay before her.

During her stay at the hospital, Deb had been prescribed a high dose of steroids to help further reduce brain swelling. To our surprise and chagrin, even after Deb harrowingly made it through the month of continuous radiation therapy, she stayed on the carefully planned regimen of increasingly higher doses of steroids. Brain radiation, as we would learn, can have the short-term negative impact of actually increasing swelling on the brain before the tumors have had a chance to start shrinking.

On such a strong dose of steroids, Deb started to dramatically gain weight and had great difficulty sleeping. Our sons and I noticed most prominently a distinct change in Deb's mood and disposition. She slowly developed a short temper and became more easily confused and agitated at times, especially if something around the house was not occurring the way she perceived it should. Given all Deb was undergoing, all the meds, the radiation, the large tumor in a delicate area of her brain, who could ever question or not expect a change in Deb's demeanor? Taken as a whole, however, Deb was still not just leaping tall buildings, but now mountains.

Trapped in the Battle Again

But still, during those times and the weeks that followed into the summer of 2005, I had the first of many discussions with Thomas and Steven about what could be expected and some of the changes they might observe in their mom from having so much brain radiation and being on so many strong medications such as steroids.

From the day our "Irish Twins" became so, they made us so very proud of them. We could take them anywhere with us and do anything with them and never had a fear or concern about them acting up. That little old man in the restaurant noticed that of our then-one- and two-year-old sons right off the bat, before giving us a foretelling and wakeup call I should've better heeded.

I don't know how Deb and I could've ever managed without their having been so mature and responsible for their ages. Clearly, their mom's superhero blood was coursing through their veins. Few parents can boast of having two sons less than eleven months apart who had never even been in a single fisticuff. They grew up not just brothers, but best friends, always sharing and learning from each other. I remember one evening Deb and me standing in one of their bedroom doorways watching them when they were around eight or nine. They were patiently and intently collaborating as they worked together to reassemble my old desktop computer they had just ripped apart. Deb walked away shaking her head and laughing.

"My God, before we hooked up, I could have never dreamt I'd be spending the rest of my life with a computer nerd, much less three of you!"

Deb famously shared with others that she had to resort to, "mounting the keyboard on the headboard and making a nighty out of floppy disks!" While Deb loved to tease me, we talked many times about how grateful we were that some children were followers, being led and often running the streets. Most often, our boys could be found together exploring their talents and fascination with creating things, computers, and software. Growing up, we tossed around a football and played catch, they enjoyed bike riding with their friends, and we had many trips to the beach and fishing excursions with their grandfathers. But unquestionably, their primary interest was technology from their earliest days, barely able to sit on my lap playing with my keyboard and mouse.

Whether it was technology or having to grow up way too quickly, they always seemed to be three-going-on-thirty. More than anyone in our lives, we were so blessed that among the ones we could always count on the most were the ones we loved the most: our sons.

The month of May 2005 passed with no scheduled medical appointments. Deb's major challenge was adjusting to the regimen of steroids. The side effects from the RFA surgery leveled off and did not get any worse. But the drooping of her eyelid was now very pronounced, as was the feeling of tightness in her chest, numbness in her arms and hands, and pain that she characterized as a pinched nerve. While her HOA did not materialize as badly as prior episodes, the changes in her fingers and nails were a little more evident, causing me to wonder if the RFA really worked or if cancer was lurking elsewhere in her lungs as that was the cause of her HOA.

Toward the end of May, Deb surprised me in the most wondrous way that I could have never foreseen coming. One morning she startled me, noisily opening the French doors leading into my office in the front of our home. She stuck her head through the entrance with a serious look on her face.

"You need to take a break and come in the front room and sit with me for a little bit. I have something to tell you and we need to talk."

As she slowly turned and walked back to our living room, leaving Cody dutifully trailing behind her, I began circulating all the various scenarios of why I was being busted. I centered on my certainty Deb had gone into the filing cabinet and tried to find our current billing and the insurance statements. Since her RFA procedure and the one-week stay at the hospital when her brain cancer was discovered, Deb alternated between her fury at me for not divorcing her and asking if the billing was in the mail. In recent days, she had become more persistent and my standard answer was wearing thin.

"Well, you know, Babe, how long doctors and insurance companies can take."

As I was home every day taking care of Deb, I had the opportunity to start cherry-picking the mail. As a notorious night owl, I would only go through the bills after Deb was tucked away in bed fast asleep with Cody during my night shift. I long ago removed the billing files from the cabinet and had them hidden in my office. But the day before, as I was retrieving the mail, I noticed Deb's reflection through our lead-lined, frosted, etched-glass front door. Deb was standing there waiting for me to come back in.

Knowing my every move was being carefully surveilled, without taking the mail out of the box, I quickly sorted through the items, making certain there were no billing statements. My new plan was to leave those in the box until I could sneak out on my night shift or smuggle them in after my evening walks with Cody.

Sure enough, as soon as I opened the door, Deb was standing right there in my face with her hand out. I knew that unquestionably sooner or later the chickens would come home to roost. But for now, and as long as I could get away with this little routine, the only thing I wanted my wife to focus on was the care battle, not the financing of the care battle. I did my level best to shield Deb from the cold, steely facts. We were shelling out over $2,000 a month on top of our $1,100 monthly COBRA premiums. With what we owed the hospital and the medical center from the three-month nightmare, plus all the new bills, we were over $30,000 in the hole at that point.

But as I sat down next to Deb in the front room, she left me thoroughly and wonderfully dumbfounded. I could not have been more wrong in my situational assessment and circular mind games. Deb started our conversation with a serious look.

"I decided I wanna go home. I wanna see where I'm from."

My first thoughts were bewilderment that Deb wanted to go back to the South Side of Chicago, of all times. But then she did grow up there, and that's where she lost her dad.

"So you want to make a trip back to Chicago, Babe? When do you think you want to try to accomplish that?"

Now Deb was the one looking perplexed. She riffled through that day's newspaper on her end table and from underneath the stack pulled out the atlas that had once been on one of my bookcase shelves. It was opened to a map of Europe.

"Hell, no. I don't wanna go back to that damn place! I want to go back to where I'm from. You know," she pointed to Europe on the opened page in the atlas, "but I can't find it on the map. Can you show me where Holland is on the map? If you can't find it, Ma knows where it is. Call her up and she'll tell ya."

I found the entire conversation intriguingly precious and the rest of that day glorious. I have to admit I was so startled at first. I even kind of looked at the map sideways. But I recalled something to the effect that Holland was really the Netherlands.

As I shared that high school geography brainteaser from a distant past with Deb, however, she was not having any of it!

"Bullshit. Ma says we're Dutch and we're from Holland. So

Holland is Holland. Just call Ma; she'll tell ya where to find it. Call Ma."

Deb was not done with what she expected to accomplish as the boys were out of school for the summer.

"I also want us to go back to the Keys where we made TC, and I want to swim with the dolphins."

Now, this request did not take me entirely by surprise. Debbie talked about wanting to swim with the dolphins the previous summer but we were too preoccupied with the potential move to another state. Way back when, based on the calendar and the news from the doctor at the time, it was our best guess the magic moment Thomas, aka TC, came to be was when we vacationed for a week in Key West in 1987. Thomas's middle name was for my Uncle Calvin, who I was extremely close to my entire life. Deb started calling Thomas TC from the moment the nurse handed him to her.

Deb was on a roll. The morning of surprise requests was not yet complete. "I want you to make me some bacon. Maybe make some eggs with it. I saw on *Oprah* where if I eat bacon every day, I'll lose weight. They called it, the cattle diet."

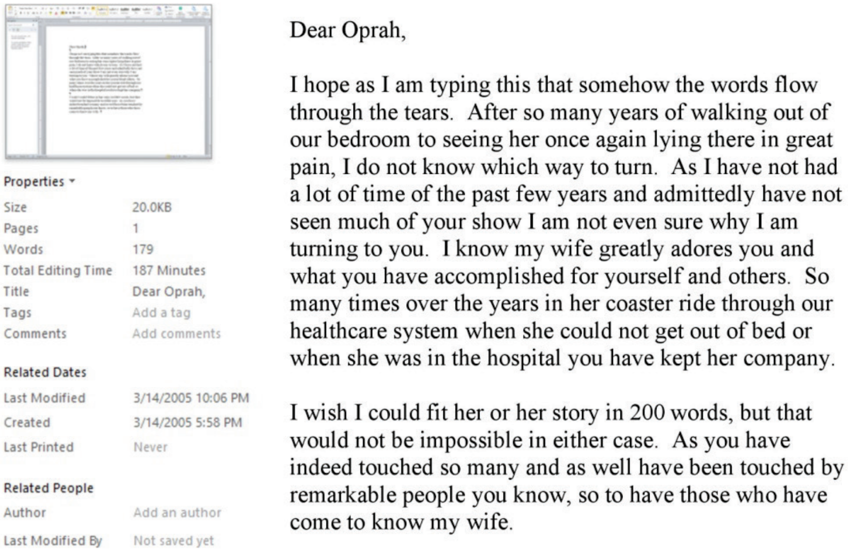
Now I was the one that was a touch confused. "But Baby, bacon is from pigs, not cows. But I'll gladly hustle up some eggs and bacon if that is what you want."

Now even more frustrated with me, Deb shook her head and waved her hands. "Don't you think I know where the hell bacon comes from, silly? I don't know why they call it the cattle diet. But that's what they call it.

"Oprah and that doctor on there say if you eat bacon every day and stop eating bread and potatoes, you'll lose weight. And I'm sure as hell gaining it from all those damn pills. I can't fit my fat ass in anything anymore and that shit has got to stop. Oprah says if I eat bacon, I'll lose weight. So I need to start eating a shitload of bacon."

Above all other stars in the sky, or at least those in Hollywood, the one that Deb revered, worshiped, and dearly loved the most was Oprah. Many years before, Deb had given me a VCR recorder for Christmas so that I could always record her favorite shows, *Oprah* and *Judge Judy*. Even when we were away, such as at her doctors or hospital, Deb insisted that everything was set up so that her show was recording while she was gone. The maddest she had gotten at me in a long while, was when I screwed up one of the times Deb was in the hospital and she missed an entire week of her *Oprah* shows.

One week after we had seen the Eagles, as Deb was quickly spiraling downhill just before her brain cancer was diagnosed, I did reach out to Oprah, or at least to her website. March 14, around 10:06 p.m., more precisely. Rereading that note I typed in Word and pasted into the "contact form" of Oprah's site, admittedly all these years later I am not certain what I had hoped to achieve within the 200-word constraint of an electronic message box. But hopefully, whoever had the job of reading Oprah's countless thousands of adoring messages, knew of at least one loving fan that was as special as she was.



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Comments	Add comments
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Created	3/14/2005 5:58 PM
Last Printed	Never
Related People	
Author	Add an author
Last Modified By	Not saved yet

Dear Oprah,

I hope as I am typing this that somehow the words flow through the tears. After so many years of walking out of our bedroom to seeing her once again lying there in great pain, I do not know which way to turn. As I have not had a lot of time of the past few years and admittedly have not seen much of your show I am not even sure why I am turning to you. I know my wife greatly adores you and what you have accomplished for yourself and others. So many times over the years in her coaster ride through our healthcare system when she could not get out of bed or when she was in the hospital you have kept her company.

I wish I could fit her or her story in 200 words, but that would not be impossible in either case. As you have indeed touched so many and as well have been touched by remarkable people you know, so to have those who have come to know my wife.

Learning Opportunity: *If all else fails, reach for the stars! My message to Oprah!*

But I immediately ran into showstopping complications fulfilling Deb's wish. Deb or I rarely ate a heavy breakfast and we had no bacon in the freezer as we typically did. As I look back on that day, it seems as so often in life, something simple leads to something unexpected. You make a right instead of taking that left. In this case, simply having no bacon in the house would lead us to have one of our last joyous non-medical days out of the house.

"Tell you what, Babe. You have questions about where you're from and obviously, we need to do some planning. Why don't we get out and go get breakfast? You can get your bacon, and on the way home, we can stop at the bookstore and get some books on Holland and the Netherlands."

Deb quickly agreed. "Yeah, let's do that. But I told you, I ain't going to no damn Netherlands or Chicago. I wanna go to Holland. I want to get that book on Holland."

With her Cody-bear by her side, she also made another addendum to our now-growing to-do list during our impromptu and rare trip out of the house. Deb was always thinking of her Cody-bear, aka, "Biscuit-butt!"

"We can go across the street when we're done eating and go by the pet store. I want to get Cody-bear some more biscuits and a new beef bone." Deb now had Cody dancing in circles around her as she teased him with what she was going to bring home for him.

I honestly didn't think Deb would make it much beyond breakfast. But as if someone switched her steroids for speed that morning, Deb had amazing energy and stamina, seemingly out of nowhere. In addition to everything else on Deb's list that we accomplished that day, from bacon and eggs to dog bones and books about "Holland," we even stopped at a local store so she could clothes shop. Doing her best modeling moves coming out of the dressing room, Deb had herself, the ladies at the store, and me all cracking up as she modeled what she called her "starter Moo-Moo dresses," while delivering her best impersonation of a cow mooing. Deb teased she was getting as big as a cow and made light of it in the moment. But living in her private world of torment, anguish, and embarrassment over her growing size, made that moment all the more remarkable and memorable.

She told the gal assisting us all about why she would never have to worry about graduating to the next Moo-Moo sizes. She carefully explained how she was going to lose her "fat ass!" Deb presented with great seriousness the "cattle diet" and how she had, "just got done eating bacon" and would start eating it every day. She encouraged the bemused staff to listen to Oprah and do the same. I found out later in my Internet travels that Deb had mistaken "keto" for "cattle." No wonder we were all humorously perplexed!

I did not realize at the time, looking back on that day in the years to come, how very precious and cherished it would forever become. A special day spent with a special superhero, thanks to another superhero, Oprah and her "cattle" diet!

The beginning of June marked the return to more appointments. On June 6, Deb underwent another brain MRI and bloodwork. On June 8, she had another PET scan. On June 10, Deb had a jammed day, with CT scans of her chest and abdomen in the morning. In the early afternoon, Deb had appointments with the radiology oncology team and would close out the day with a visit with our dearest Dr. Elizabeth.

I was pleasantly amazed by how well Deb handled those scans compared to all the years previously. It was apparent the way Deb walked out of the back afterward, having to endure the brain radiation therapy made those other procedures much less torturous and difficult than before. As we sat with Dr. Elizabeth, she would share the most delightful and immediate news.

"Based on all the tests, I think we can begin a very careful regimen to slowly reduce your steroid dosage. Just as we had slowly increased the dosage, now we will reverse the process and slowly back you off the steroids."

The initial interpretations of the scans appeared to have Deb taking one step forward and a half step back. Dr. Steven, the radiology oncologist, shared the wonderful step forward—all of the radiation treatments had a positive impact on her brain cancer. The two smaller tumors did not show up at all during the scans and the one that was the size of a golf ball was reduced in half, or so we were told at the time. The half step back—we learned from Dr. Elizabeth that while the procedure performed in her right lung appeared to disintegrate most of her cancer, there was still one small unreached area remaining that was in question.

Throughout June 2005, several attempts were made to gradually and carefully wean Deb off the high dose of steroids that had been contributing to much of her misery. But each time, just as she would reach the final stages of the complicated regimen designed to carefully reduce the dose, Deb's original brain cancer symptoms would materialize. The end of June, after the third attempt, culminating once more in Deb not being able to move from her bed, I found myself again trailing an ambulance back to the hospital. During the rush hour with a massive traffic jam near the facility, the trip took much longer than normal. Given Deb's vertigo, dizziness, nausea, and pain, she later recounted that the experience was excruciating.

I will never forget watching those minutes fold away knowing what was happening inside that ambulance and feeling so many emotions as I finally lost sight of the box slowly maneuvering past the parking lot that was supposed to be a roadway. I arrived long after Deb to find her already in one of the E/R rooms decorated with the monitors and IVs connected to her. Soon thereafter, our beloved Dr. Elizabeth arrived and took charge. As she started the admitting process, I once again found myself standing outside the E/R. attempting to communicate all-too-familiar words to our courageous sons. I would again be spending yet another night at the hospital with their mom—a father-and-son phone conversation that tragically was their reality for far too long and way too many evenings.

Thankfully, this would be one of Deb's shortest hospital stays on record. With the steroids raging again within her system, she stabilized and could open her eyes and sit up in bed without the room spinning unmercifully in dizziness and nausea. After many more tests and scans in the days that followed, we again met with Deb's radiology oncologist, Dr. Steven. This time we received a markedly different determination of the remaining brain tumor than before. Rather than a fifty-percent reduction as we were initially told, the tumor was in fact almost the same size as before all the radiation.

On June 29, we met again with the lead radiologist oncologist and the neurosurgeon, and Deb's superhero mettle would now be tested again in all of the worst possible ways. Deb was fortunate to now be in the care of a skillful neurosurgeon who took much time and great care with her. It was decided that she must immediately undergo a procedure called a "Stereotactic Gamma Radiosurgery." Also known as a Gamma Knife, the treatment is a highly precise non-surgical radiation therapy using focused X-ray beams to attack the tumor.

On July 1 at 7:30 a.m., we arrived at the radiology oncology outpatient surgical unit. Deb began a series of pre-op procedures that would prove to be extremely intense and difficult for her. Thankfully, for the most critical procedures, Deb would be sedated. It felt as if she was trying to hug me forever until the moment she was gowned and prepared for general anesthesia. Deb was petrified, given the terrifying experiences of her previous brain radiation treatments and the knowledge that this procedure required the use of a halo frame. Shockingly, it would be secured in its own pre-step procedure.

After Deb was "put to sleep," four large pins were screwed directly into her skull. For the actual procedure, a large halo is locked into place using those pins for the delivery of an exactingly precise series of high-intensity radiation beams that would converge in a highly orchestrated pattern on the tumor. Once the pins were in place, the halo was literally screwed onto Deb's skull. She was then awakened from the initial procedure and brought to a room where we nervously waited for many hours.

Nothing written here could adequately describe the surrealness of those intervening hours sitting by Deb, gawping at how she so bravely addressed the huge, heavy frame bolted into her skull. Meanwhile, Deb's "dream team" worked on crafting a delicate, three-dimensional, computer-aided model of her brain. This would be used to precisely deliver the Gamma Knife. In addition to her radiology oncologist and a neurosurgeon, Deb's team included a radiation physicist, a neurologist, and a dosimetrist—whose job is to carefully calculate the dose of radiation. A team of radiation therapists would assist the medical team and Deb through the three-hour Gamma Knife operation. Thankfully, Deb would be under general anesthesia.

After all the calculations were finalized and the planning completed, around 3:00 p.m., Deb was taken back to the outpatient radiology surgery room and the Gamma Knife procedure began about thirty minutes later. Every hour or so, someone from the magnificent team would brief me with an update. Everything proceeded exactly as planned, and after an intensely long day, shortly before 7 p.m., four hours since I last saw her, I was sitting with a groggy Deb in recovery.

We arrived home very late that evening exhausted. After a couple of cups of her cherished coffee, Deb ate very little and immediately transitioned to the bedroom after getting warm hugs from the boys. With her Cody-bear as always snuggled at the bottom of her side of the bed, they both fell quickly asleep. Early the next morning, I was awakened by Deb softly crying. When I rolled over, she was sitting up in bed running her hands over her head. We had already been forewarned that it was almost a certainty Deb would lose the remainder of her hair this time around. As forecasted, with every wave of her hand over her head, Deb had a hand full of hair.

"Are you OK, Baby? I'm so, so very sorry." My tears now joined Deb's as we hugged for many minutes.

Superwoman, however, demonstrated that sometimes even kryptonite doesn't work on a superhero. Deb pulled herself together more quickly than I would have ever believed possible, given how she felt about her hair among and above all her other physical changes. Continuing to cry softly, Deb made her way into the bathroom. As best as Deb could, she slowly wiped away the rest of her already loose hair with a towel. She then went straight into our closet and emerged with one of her new wigs as I stared on, frozen. Deb had ordered those after her first round of brain radiation during the month of April.

Deb stopped at our bathroom mirror and adjusted her wig to get it the way she wanted. Then she was off to the kitchen to crank a pot of coffee with her ever-devoted Cody-bear trailing alongside. I lay in bed staring up at the ceiling fan whirling away, replaying in my heart the scene that just unfolded before my eyes as they were jarred wide-open to start an insufferable day. It was my turn to pull myself together and try to match what Superwoman had just accomplished, "in a single bound!"

For a time going forward as Deb did not like to wear what she called "do-rags," she would always wear one of her wigs, except in very private settings and around me. She did not even want to bare her head in front of Thomas and Steven at first.

"I don't want to scare the living shit out of them," she said when I inquired after the first week of her steadily losing her hair why she wore her wigs around our home.

"Baby, you don't have to wear that for the boys, or for that matter anyone, if you don't want to. You are so beautiful no matter what, and yes, even with no hair!"

Regardless of how beautiful she truly was or how I presented that fact to her, she refused to accept the truth.

"Bullshit. If I would have walked into that convention center the way I look now, you would have backed up like a car in reverse and hightailed your ass to the exit."

Her strength was amazingly at times undaunted. There were occasions when Deb's sense of humor, even naughty at times, broke through difficult and tragic times. She and I laughed and laughed when she pointed to her head.

"I know you got all turned on watching that *Coneheads* movie, but this ain't no damn cone!"

Continuing to point to her head, she said, "And you better not wake my ass up in the middle of the night and let me catch you playing with this and then that." I'll leave it to your imagination where Deb was pointing when "that" came out of her.

Monsters from Within

Now weeks later, the middle of July, one year after they last saw each other, my cousin Sue and Deb were once again reunited. This time it would be Sue and her husband, John, that came our way. Honest to God, I'll never understand how Sue ever made the journey on that day. Deb and Sue had done a better job keeping in touch during the year that had so quickly and painfully passed. But it was often heartbreakingly difficult for both given their respective care battles that had transported them both once more unto the battlefield.

Sue's journey over the past year was as torturously tragic as the road Deb found herself traveling. Over the last half of 2004, Sue had been hospitalized three or four times with stomach problems after her first rounds of chemo and radiation. Each time, Sue would receive few answers from her local oncologist and the small-town hospital.

Sue started 2005 much as Deb had. While Sue's uvula cancer was being treated, she evidently had another tumor that had been lurking on the backside of her lung that was not discovered and had metastasized to her liver. Without further treatment, her doctors only gave Sue seven months to live. In a painful decision for my cousin and her family, Sue decided enough was enough.

Deb and Sue sat together on our living room couch holding hands and sharing their battles and other stories through their laughter and tears. Both knew this would be the last time they would see each other. It was heartwarming, heartbreaking, and heart-wrenching all rolled into one afternoon.

As I stood in the kitchen with John preparing lunch, he and I just kept looking out into the living room at the scene unfolding before our eyes. Once again, two battle-hardened veterans comparing notes and battle plans and all that had befallen each since they last saw each other. Deb could bare her soul and everything else to one of her bestest buddies. I was not surprised when Deb took Sue into our bedroom and shared the results of her latest battlefield skirmishes.

As Deb was growing in size, Sue was shrinking into oblivion. Watching the two of them together, John and I could only exchange often teary-eyed glances at each other as we quietly talked while I rattled pots and pans. We dared not look at each other for too long or risk, at least in my case, completely breaking out into a teary waterfall. I listened as Deb had waited until she was with her buddy to talk about things she had never spoken about before or even gave me a clue she was contemplating. But looking back, how could she not?

That afternoon would be one of the first moments I would realize that the evil foes Deb was battling were truly starting to maneuver onto higher ground. Sue bravely expressed her firm desire that she did not wish to die at home. Sue and John had started looking into hospice care facilities where Sue might go when it was her time. Sue did not want their oldest son, Jason, to be a party to her final moments on this earth. Buddy, as the family had nicknamed Jason, is a wonderful, warm, and engaging young man who was born with Down syndrome.

Sue expressed how blessed she felt to have had the previous months of shopping adventures and times with her sisters and her mother, my Aunt Margie. She and I were extremely close and my heart was heavy for my dad's sister. While Sue seemed resigned and ready for the next journey ahead, she as well lamented the tragic fact that somehow while her doctor was treating her throat the year before, the tumor in her lung was either missed or rapidly materialized out of nowhere and then spread just as rapidly. But Sue said she was not surprised. She knew after she had her throat treated, no matter what her doctor said, she felt she was, "not free of it."

Sue was singing to the choir, and they to each other as Deb had as well remained adamant during her year of "remission."

"Cancer always returns. It's just a matter of when and where!"

I should not have been so totally caught off guard when for the first time I heard Deb share with Sue her thoughts and plans, "if" her days were stretching to their final most human frailty and outcome. Deb was starting to determinedly contemplate her own mortality.

"I ain't going anywhere but parking my fat ass in my bed. This is where I want to be, with Walt and my boys and my Cody-bear. We have lived through all of this shit together. We'll live through the end together, and I know Walt will take good care of me. He always does!"

It was a foregone conclusion watching Deb over the past four and a half years, including recent months, that one of the toughest of the tough to roll out of the South Side of Chicago, could never have had such thoughts until the bitter end. I was, after all, married to the real Superwoman.

Neither one ate much of their lunch as they continued to reminisce about the good days, the fun days, and as John and I would listen, flabbergasted, some extremely expensive and naughty days. Shopping adventures the likes of which I had somehow managed to overlook in my reviews of our credit card statements in prior years. They laughed so hard, the tears now flowing down were out of camaraderie and those cherished memories of days of old, rather than recent journeys leading them to this most dreadful of destinations.

Sue and John, my Aunt Margie and Uncle Bernie and cousins Dean, Greg, Danny, Lisa, and Cindy, all lived in the same town where Deb had lived when she and I first met. Not only were they among the first of my family to meet Deb, we frequently saw much of them in those beginning days and over all the years. John and

Sue's youngest son, Jeremy, was around seven or eight at the time and he quickly developed a huge crush on Deb. She thought Jeremy was just adorable and always laid on the charm. Deb made a very warm event out of asking Jeremy to be our ring bearer. John always teased Deb, "You know you're ruining my boy for life, don't you!" To this day, Jeremy still allows me to get away with calling him Deb's adoring nickname, "Jer-bear!"

Deb and Sue did not want to say goodbye. They did not want to have that final hug. For Sue to make the two-hour trip and be out of her bed for so many hours in the condition she was in, said everything and more about how she felt about Deb and the sisterly love they shared. Sue's brother Dean and I often refer to each other as brothers from another mother. During the months after they first met, Sue and Deb became sisters from another mother.

We had many adventures and many special times together and Sue and Deb, evidently, even more, individually. In a single afternoon, it was as if all those years flashed before our eyes, culminating in that last final long hug and tearful goodbye. For the next several weeks, it remained painful and difficult to even talk about Sue's visit without becoming emotional. Deb was in deep doldrums, as I was equally awash within agonizing thoughts of my cousin and my family. Also, yes, about those things Deb shared with Sue that she had never shared with me before.

It would take a return to the then-present reality of Deb's continuing fight to not yet leave the battlefield that would whipsaw us back to advancing forward again. The first week of August 2005 through the middle of the month, Deb had another series of CT scans on her chest and abdomen. She also had another brain MRI and lab work in preparation for her follow-ups with Dr. Elizabeth and her radiology oncologist, Dr. Steven. Only four weeks out from the Gamma Knife procedure, we did not expect the tumor to have reduced in size, and that was confirmed. However, what Dr. Steven also shared produced an immense and unremovable smile that Deb wore for days.

"Let's start to try and back you off those steroids again."

Deb was once again placed on a regimen designed to slowly reduce her steroids. The timing was perfect. For the past year, we had wanted to get together for dinner with our dear friends Arnold and Laura. As I had not worked for the health plan or one of their operations in a few years, Arnold and I did not have much of a chance to see each other professionally. But from time to time, we would get together for dinner when Deb was able. Laura would also occasionally outreach to Deb, who so enjoyed their chats.

Deb had immediately taken a strong liking to them at their first meeting, and she was very taken with Laura. Deb always commented on her beauty, grace, and elegance. We had not seen them at all during 2005 and it was a very special dinner that evening. Even though Deb had changed much since they last saw her, neither Arnold nor Laura would in any way indicate so as Laura complimented Deb on her hair and dress. It was as if only the week before we had last sat at the table with them, rather than the year it almost was. But then, it was always that way with Arnold and Laura. Time stood still.

But within days, Deb quickly lost her smile. As with the first attempts, within two days of the new dosages, Deb again started to develop headaches and blurry vision. She easily lost her balance and the room started to spin again. The only recourse was to once more retreat to Deb's previous doses.

The news we received on Sunday the 4th of September, could never have come at a good time. But it came at one of the most exceedingly difficult for us with all that was already swirling around Deb, including her room. My cousin Dean called and shared with great sorrow that his sister Sue had passed. As she wished, and as if a master plan, Sue and John were at a hospice care facility that Friday just to "check it out." Instead, given how rapidly Sue was declining, she ended up "checking in." Two days later, Sue passed with her family all around her. I do not believe, looking back upon those events and times, that Deb ever truly recovered from losing Sue, most especially only six weeks after we last saw her. It was a tragedy upon tragedy.

Over the weeks to come, several more times her team again attempted to reduce the steroids, but each time Deb started to relapse and the dose was increased again. After the recent episodes, Deb underwent again another series of CT and MRI scans of her brain and another meeting with Dr. Elizabeth and the radiology oncologist, Dr. Steven.

Throughout the month of September, in addition to more scans, lab work, and visits with her oncologists, Dr. Elizabeth and Dr. Steven, Deb was now also seeing her neurologist, Dr. Kurt, and endocrinologist, Dr. Melissa. We were again living the holy grail of healthcare, a diverse team of specialists all collaborating in real time as Deb's dream team worked together to manage her case.

But every team needs a quarterback, and unquestionably, Deb's quarterback was our beloved Dr. Elizabeth. As Dr. Elizabeth so often did, she plucked out of the mountains of complex information one fact that was overlooked and had helped Deb dramatically. A blood test many months before revealed that Deb had a very unusual thyroid count.

While obtaining Deb's care from a single place where we were out of network was killing us financially, on the care side we were immune to the distributed process of disconnected care and delay most Americans endure. Back then, as now, no health information highway really exists, and the only thing connecting all your medical providers is a fax machine.

Within a half hour of her discovery and suspicion, Dr. Elizabeth had another blood test performed and read. It confirmed that Deb's thyroid was no longer functioning, very possibly a casualty of all the radiation she had many years before on her right lung and neck at the start of her war. We were hopeful that some of what was once assumed as complications from the brain tumor was in fact Deb's thyroid condition.

We also learned that somewhere along the way, one of Deb's ribs was broken at the top of her shoulder where it joins with the rib cage. This serious break did not appear on the scans from just a few weeks before. As the pain in her shoulder dramatically increased during and after the very CT scan that now confirmed the break, in all likelihood it happened when the nurse walked up behind Deb and without any warning, quickly raised her arm above her shoulder for the procedure. We were dismayed to learn that there was no treatment available that would mend the rib other than time and more pain medication.

From her follow-up appointment with Dr. Steven the radiology oncologist, we learned that the Gamma Knife procedure had not reduced the size of the tumor as we had been first told. This was why Deb relapsed with every attempt to reduce the dose of steroids. While there continued to be no change in the brain tumor, that was also in a way good news. The tumor was not growing, and there were still no signs of the two smaller tumors. It still could take many months before the benefit of all the radiation Deb had had would take effect, so Deb's core team (neurosurgeon, oncologist, radiology oncologist, and husband) all felt that the tumor would reduce over time.

Throughout the month of October, I watched Deb wage another battle in the overall war. She had awakened in pain—fell asleep in pain—only to awake hours later to start the battle again. For months, there had been no nights and no days, just Deb's relentless fight to survive. After so many weeks, now months of being on a powerful dose of steroids to control the swelling on her brain, Deb's weight gain was significant and the former model was having great difficulty adjusting to her physical changes, especially gazing into the mirror at a round face for the first time in her life.

I started to notice that Deb was now having more and more difficulty comfortably fitting into her "starter Moo-Moo" dresses, as she disparagingly referred to them. Seeing how much Deb agonized over her weight gain, I did not want the day to come when we would be confronted with having to replace those with larger sizes, further crushing her and piling more on top of everything else. Deb even started taking about cutting back her dose a little on her own. I started feeling as if I had to stand guard and watch her take every pill. While I did not wish to go behind Deb's back, nor be sneaky, I would do anything, everything, to try to ease her pain. So often during the battle, I felt helpless and hapless, unable to help Deb steer clear of landmines of distress and devastation. But this I could do, or at least attempt to do so.

I went into our closet and took cell phone pictures of her dresses and their current sizes and went back to the store where we originally purchased them on one of my extended grocery runs. Unfortunately, the store only had, as I recall, roughly half of the dresses we purchased before. But at least those were available in a larger size that would more comfortably fit Deb without being overly obvious that they were much larger.

But I was in a quandary as to what to do about the rest of her dresses. During one of my frequent chats with Mr. Bill, who tagged me often to check in on us, I explained my dilemma. True to form, Mr. Bill came up with the obvious albeit duplicitous suggestion.

"Accidentally destroy them in some way so Deb would have to replace them."

Taking that seed, Mr. Bill and I bantered around possible solutions over a drink at our local watering hole and grill during an extended grocery shopping adventure out. Mona, our bartender, a good friend and ear over the years, was now involved in our grand scheme. The group consensus was bleaching the dresses out in the wash. On my night shift, I washed and dried the new dresses many times in a row so Deb would not know that they were brand-new. I snuck into our closet and replaced those first. The next day, making certain to announce I was doing laundry, I took the remaining dresses, put them in one load, and spotted them here and there with globs of bleach. I then let them sit for quite a while. The final step was to wash them again in bleach with hot water. They all came out one splendid tie-dye mess.

During those days, Deb was just starting to become decidedly up and down. She was the proverbial box of chocolates. "You never knew which Deb you're going to get!" Not unlike the character Sybil, Deb was some days all over the map from one day to the next, and sometimes one hour to the next. Yet she also had days when she was totally lucid and the real Deb was back in there. So I had no idea what to expect when I walked into our front living room and presented Deb with my "boo-boo" on her "Moo-Moo!" To my astonished relief and thankfulness, all Deb could do was shake her head, laugh, and poke fun at me.

"All these years you been doing laundry and you still can't do laundry? Are you supposed to be a computer genius and you can't program a damn washing machine? All the training I gave you and all the time I spent with you and now I gotta train you again?"

Deb didn't even fight my suggestion that I go get her some new dresses, which would've never happened in the old days. But she did make certain to watch me write down the size and that I understood she only wanted, “that starter Moo-Moo again.” Deb was so agreeable and amenable that day, she even liked the new dresses I picked with a big smile on her face and never even mentioned the size. She got to go shopping without having to go shopping! This also would have never happened in the old days. Deb made a comment a week or two later she thought something she was doing was helping her lose weight! I could only secretly smile and share with delight with Mr. Bill, who in turn shared with Mona the great success of our mission.

After defying all the odds, and perhaps initially watered-down treatment during her early rounds of chemo, Deb finally had lost all of her hair months ago from all the intense brain radiation. While some of her hair started to return in many places, it still was not growing in a wide track straight down the middle of her head.

No matter what I said to Deb, or how I pleaded that we would rather have seen her that way than no way, or even as she was when she was severely underweight, my words would not bear any comfort. As always and through it all, however, Deb remained the shining light and beacon of inspiration and hope to all whose lives she touched, her doctors and nurses included. I am convinced that I was married to a real-life Superwoman. Few mortals among us could have stared down so many challenges and obstacles with such courage and determination.

But day by day, I lived the private world of Deb’s pain, and through her solemn blue eyes, felt her deep sorrow. So much to bear when combined with the pain in her shoulder, arm, and hand from the recent lung procedure, on top of the nerve damage in her side and lungs from all the previous procedures and infections. Now, a broken rib and continuing headaches and blurry vision heaped onto her misery for added measure.

Deb’s courage, grit, and perseverance were there, but so too, out of nowhere at times, was her spunk in a perverse way. Several times, Deb snapped and dressed down one of our sons for something they had not done. Something she had imagined or thought she saw or misinterpreted. I was not immune, either. Deb presented me with some equally interesting insights about myself as well. She went down the list, from my “self-employed, workaholic. never-sleeping, night-owl ass,” to what she thought of my friends, including, hurtfully, Mr.

Bill. While I could take Deb's blistering with a grain of brain cancer and medicated blustering, I felt exceedingly devastated each time Deb's unevenness fell upon Thomas and Steven's young shoulders. Either in our group discussions or individually, practice under fire did not make their mom's outbursts and our resulting discussions any less difficult over time.

Our sons and I were at times greatly challenged with the many transitions Deb was undergoing and experiencing, as if the accumulation of so many physical ailments resulting from multiple surgeries, her broken rib, being given MRSA, and the RFA procedure were not enough. Now Deb suffered from insomnia and ever-increasing mood swings and irritability, and at times even mania. More consequences heaped upon Deb both independently and in a combination of the brain radiation, the location of her brain tumor, and being on such a high dose of pain meds and steroids over so many months.

We lived through continuing challenges and trying to make it through each day awash in so many emotions. As we had for five years, our little family was resigned to taking one day at a time and moving slowly forward with one foot in front of the other. For as long as I walk this earth, my pride will swell inside each time I look upon my sons. They had endured so much. Through their courage and determination, Thomas and Steven had given their parents the greatest gift any child could.

Throughout those late summer days and into the fall of 2005, there were no nights or days. Only catnaps. Increasingly Deb simply could not maintain a normal schedule or sleep pattern. Steroid-fueled, insomnia-filled nights made for an all-too-convenient canvas upon which hours of wrenching pillow talk were painted.

The Final Journey

Family Ties That Binds

The middle of October, Mom and Dad arrived for another visit. Jeanne, and many times Ken with her, visited often during Deb's war. So many years into the battle, those helping to provide the care often end up needing it themselves. I was so blessed and thankful for each of those special times with my other parents. I drew such great strength from their love and support. Every visit was the eye within the storm, much-needed tranquility and respite. Mom was my role model who I so desperately aspired to be. No matter how bad or what winds were swirling about us, our mom was calm within a hurricane.

It was I who was back to handing out candy to trick-or-treaters that Halloween of 2005. Deb never emerged from our bedroom, not wanting to be seen by anyone, much less by one of our neighbors. Knowing this was a difficult occasion for Deb, in between rings of the doorbell, I frequently went and checked on her and Cody. She said little as she quietly worked on some of the chocolate candy gems and surprises I had gotten her.

Yes, I recognize it is not logical weeks after playing shenanigans with her dresses to now be plying her with chocolate. But this was Halloween, and what the hell—if not then, then when? Besides, knowing Deb, I'm certain she was playing her favorite game, much to my chagrin, "one for me and one for Cody-bear!"

Where Deb really wanted to be was written all over her face. Emanating from those beautiful blue eyes, it was painfully evident just how difficult that evening would turn out to be. Deb had so relished interacting with all who came to our door. On that toilsome evening, and every Halloween since, I can't help but think of how lucky I was for the year before. I had that one last time to witness Deb again, so magically transformed, so bewitchingly effervescent.

Deb was also anxious and restless about the upcoming visit from our son Ray, the first weekend of November. We would be meeting Ray's fiancée, Susan, for the first time. While this would be a happy occasion, it would also be deeply saddening. Ray would be introducing Susan to his mother, in the middle of the battle of her life, beset with so many battlefield wounds and physical changes. Some injuries external and visible, others silently buried deep below the surface.

Deb was saddened she would not be able to make the trip back to Chicago to watch her oldest son walk down the aisle in early December. Yet she was also torn about seeing Ray's father again. Deb had missed so many of the special occasions and events of Ray's life. Now she was missing his biggest day. Ray's father left Chicago, taking Ray with him, when Ray was just two and a half years old. Teenage marriages are often difficult and especially traumatic when quickly followed by a child and then divorce. Deb had dropped out of high school as a freshman and got married, had a baby, and was divorced by the time she was eighteen.

One of the first times I went to Deb's very well-kept and appointed apartment, it was easy to spot the framed picture of the cute little blond boy that was prominently on display. Raised by his father in Alaska until they moved back to Chicago in his early teens, Ray never really had the opportunity to get to know his mom. Periodic phone calls sadly just did not establish much of a mother-son bonding opportunity.

The boys and I would meet Ray for the first time during the summer of 1993. Ray was seventeen and a half, and soon headed off to the Coast Guard Academy on a football scholarship. Deb was so very proud of Ray. Over the years, many who met Thomas and Steven have commented assumingly, "They have your brains." But only those who did not know Deb could presume such things. One of my attractions to Deb was her intelligence. Teenage decisions and life circumstances did not afford the opportunity to advance her formal education. But Deb was a quick study and able to apply her many talents and smarts, street and otherwise, to accomplish pretty much anything she set her mind to.

It was immediately clear, as with Thomas and Steven, Ray was cut from the same cloth as their mother. He was quite bright, mature and well-spoken for his age. Ray was a young man on a mission, ambitious and sharp as a tack. As he resembled his mother in capacity, he did so visually as well. As Steven, Ray bore a strong resemblance to Deb and they looked like brothers, whereas no one looking at Thomas and Steven ever guessed so. Thomas resembles my side of the family and there was no mistaking Thomas as my son. Those who met our family often commented that Deb and I had "one of each!" Looking at Ray it was clear Deb had two and one.

Over the years that followed, Ray got to know and bond with his mom and brothers as well as distance and the intense demands of the Coast Guard Academy and a thirteen- and fourteen-year age difference with his brothers would allow. Just as Ray was starting his post-college life and career, his mom's war with cancer started, challenging yet expanding their relationship in whole new ways. Including, amazingly at times, hopefulness, as when Ray visited in 2004 during his mom's lull in the battle. Looking back on that visit, Ray shared, "I was optimistic that in some cosmic way the illness Mom was fighting would be a catalyst to bring us together."

Just a year later, he was now bringing the young lady he would marry in four weeks to meet his mom just as she was once more engulfed in the war. Hearing about the changes occurring in his mom since they last saw each other was a vastly different reality than when instantaneously viewed as an accumulation. Young and healthy, Ray had been innocently unaware, like so many who don't know what they don't know about Healthcare in America. During Ray's visits and phone calls with his mom, he painfully learned what he didn't know.

Ray said to me he felt, "confused and angry at the system, feeling helpless for my brothers, my mom, and you."

On that important occasion, as with so many others before and after, Ray remained brave and strong. Susan was everything Ray had shared and she was wonderfully much more. An amiable beauty whose inside equally matched the eloquence of her cover, Susan was intelligent, charming, and warm. In every way imaginable, Susan was Ray's match. It is we the fortunate, who have felt lightning at the touch of another. Ray and Susan had undeniably been struck.

As Ray demonstrated great courage in the face of what he was now witnessing firsthand, so as well did his mother. Deb was steady and unflappable and never broke down or capitulated to her pain and sorrow. Deb very much got up for the occasion, and we were blessed with a wonderful few days. Susan may not have met the Deb of old, but she certainly experienced a glimpse of her soon-to-be mother-in-law's former self.

It was another painful goodbye. But neither Deb nor I wanted to frame this occasion or others to come as a "final adieu." As Susan and Ray undoubtedly surmised despite what they may have visually conjectured, Deb was still not yet ready to withdraw from the battlefield. But, what went unsaid during that last visit, the only time Susan would ever meet her mother-in-law and the last time Ray would see his mother, was as Ray would share again looking back.

"When we left the house on that trip, I remember feeling a flood of emotions. My mom would never have a chance to meet her grandchildren, nor they, her. What a great opportunity it would have been to bring us closer together and for her to finally have that little girl you always wanted."

The good and bad was Ray and Susan had experienced Deb at what would be among some of her last level-best days. Deb's condition continually worsened. In addition to profound insomnia, Deb suffered increasing headaches gradually becoming severe enough that her pain medication brought little relief. As her headaches started to escalate, so too did her dizziness. Still, Deb was insistent she would not stay married to the bed or, for that matter, me, as divorcing me was off and on still a hot topic.

Each day, regardless of how much her head was pounding or the room whirling, Deb would make her way into the front living room to spend her day in her recliner rocker. She sought some relief getting lost in her cherished saltwater aquarium and escaping into the big screen of our TV. Each day she transported herself into the audience of her beloved Oprah or in the courtroom of Judge Judy.

Usually, the boys got to go to their restaurant of choice for their birthday. But for Steven's big 16th the middle of November, it would be a pizza party to go with the cake and ice cream. Deb somehow managed to reach deep within for Steven's birthday. It was wonderful to see her smiling and standing in the kitchen in the middle of our sons, merrily singing "Happy Birthday" to Steven. I took in every second of those priceless moments. The two young men flanked on either side of Deb had grown in steely maturity and stature as both were now much taller than their 5-foot-11 mother was.

Decisions Made and Changed

Increasingly, Deb needed my assistance moving about and getting to and from the bedroom and bathroom. It was not only Deb's room spinning. During those weeks, Deb became more forceful about divorcing me after finally demanding to see the billing and where we stood with both the hospital and the medical center. We lived how cataclysmically quickly medical bills can pile up. Even as Deb kept asking me directly, I evasively danced around the numbers and her questions. Telling her none of it mattered. Only she mattered.

"How many damn times did I tell you to divorce me? Why the hell didn't you do that? Look at what you are doing to you and the boys. You still have time."

For days thereafter, the financial pain was piercing Deb as much as the sundry of other battlefield wounds she had accumulated. She now continued in full force with the idea she got in her head and there just was no shaking it. If only I would divorce her, she could become a ward of the state and erase the medical bills we had already accumulated, and she would be responsible as well for any of the new bills to come as she continued the battle. Deb alternated between begging and commanding me to file the paperwork.

As Deb persisted, I grew despondent and demoralized that she felt compelled to divorce me. In the middle of so many tragically difficult concerns and events unfolding, these were Deb's thoughts. Tragically, in all the years since, Healthcare in America has only gotten more costly and complex. I live in a country where after several decades of marriage, a wife feels she must leave her husband so she can stop the bleeding. Not hers—that of her family.

"Why in the world, or in all places, America, would a wife and mother have such thoughts?"

But, sorrowfully, financial fears were not the only ones guiding Deb's resolve whether to continue the battle or not. She was literally "scared into death" at the thought of going back to the hospital, given all the painful experiences that seemed to continually plague Deb there. Five-percent chances of anything going wrong. Yet they always did. Deb shared it most simply and bluntly in her South Chicago style at varied waystations along her torturous journey.

"I can't beat the odds playing the lottery, but I hit the jackpot every time I go to that damn hospital."

Deb would soon again lose at the healthcare roulette table. I was on point to manage Deb's complex regimen of daily medications including her large pillbox that I loaded weekly for each day of the upcoming week. I noticed after picking up Deb's meds, that her main pain drug was not the same. I immediately called the pharmacy. They quickly shared that our insurance company no longer had the brand name on their formulary so they switched us to a generic. I could have the brand name, but at an outrageously high price.

The pharmacist assured me that Deb would notice no difference. I loaded them into Deb's pillbox. That evening, I gave Deb her meds, including the new generic. Within hours, Deb was in pain. She had no idea I had handed her a generic. But her body knew. Over the course of that evening, Deb was in much pain and it was clear something about the generic was not working in the same way as the brand name. I called the pharmacy and the pharmacist on duty shared while it was rare, it was possible the generic was not working for her. I should contact my insurance.

But in order to quickly get Deb out of pain, I had no choice but to purchase the brand name out of pocket and fight with the insurance company after the fact to try to get it approved. But even at that, I had another huge complication. Once filled, Deb's prescription could not be used again. It is not as simple as just swapping out the generic pills that did not work for brand name and reaching for my credit card to pay for it. But I also knew in addition to having to get a new prescription, the real battle would then commence in trying to get the insurance company to override their formulary on appeal.

Approaching Thanksgiving 2005, Deb had now spent nine months battling the agonizing side effects from her last lung tumor procedure, the RFA she had in February. Nine months of avoiding mirrors, not wanting to see her detested droopy right eye. Over those months, the loss of strength and numbness in her right hand and arm and a constant tightness and numbness in her chest only got worse. For the last six months, we had continued to play a waiting game since her Gamma Knife procedure that cost Deb her hair, hoping the radiation would wipe out the last vestiges of the large tumor as it had the two smaller ones. For six months, Deb valiantly tried to keep down the massive and complex daily regimen of over a dozen different drugs.

But, just before Thanksgiving Eve, everything came unraveled once again. Deb spent days completely unable to get out of bed due to increasing severe dizziness, nausea, and an inability to keep anything down, including her medications. She was badly dehydrated and started to develop mouth sores. Deb was caught in a perverse circular firing squad. She was unable to keep her nourishment down, making it more difficult for her to keep her meds down. Unable to keep her meds down, most importantly her pain pills and steroids, made the headaches, dizziness, and vomiting worse, causing further dehydration.

I was glued to Deb's beside with a bedpan. Also glued was Deb's stubborn Cody-bear. At times, he even refused to obey my command to "heel" so I could let him out into the backyard. Cody and Deb shared a uniquely special bond beyond anything I had ever witnessed before, even for a German shepherd. Once more, how so very wrong that K-9 officer was three years before in his assessment and prediction of the kind of family member Cody was going to make.

I found myself again pleading with Deb to allow me to call an ambulance. I knew even if I could persuade her to go somewhere, even with the assistance of our sons, I'd never likely get Deb into our tribe-mobile, as we had dubbed all family vehicles. Deb could not even sit up in her bed, much less get up into her seat in our SUV. But my forward-thinking was for naught. Despite my pleas, Deb refused to budge from our bed.

"There's no damn way I am ever having my ass shoved in the back of an ambulance again, especially to go back to that shit-ass hospital. I'd rather lie here and die. I ain't going nowhere!"

Watching Deb suffer as the hours unfolded, I again defied her orders. In the mid-evening hours, with nowhere else to turn, I shined the "bat-light" into the sky as I turned to my other superhero. I picked up the phone and called our physician angel at her home. After speaking with me for only a few moments and certainly hearing the distraught ring in my voice, Dr. Elizabeth reacted in an almost unheard-of manner. Especially in this day and age of Healthcare in America, Dr. Elizabeth promptly got in her vehicle and made a house call.

I paced back and forth, in what most certainly were tens of minutes that seemed tens of hours. Seeing Dr. Elizabeth pull into our driveway was a godsend, and I immediately went out and greeted her. We hugged warmly. As Dr. Elizabeth walked through our bedroom door, Cody immediately came over and greeted her as Deb drew a slight smile upon her face. The first I had seen since Ray and Susan were there. If Dr. Elizabeth was leery of big dogs, she did not display it. After a quick hello to Deb's one-hundred-twenty-pound baby, I had Steven take Cody out back and then into his bedroom.

I still envision Dr. Elizabeth sitting on the side of our bed holding Deb's hand. She was softy speaking to Deb as she examined her and then holding a cool washcloth to Deb's forehead. Dr. Elizabeth could not shield with any doctor-patient veneer the pain in her eyes any more than Deb could.

Looking across the room at the two of them together through the glow of the dimmed bedroom lights, the complex four-and-a-half-year journey spent as patient and doctor was clearly evident and evolved to be much deeper for both. Dr. Elizabeth had come to Deb's rescue so many times before. But there late into the night, only then did I start to grapple with what most probably Dr. Elizabeth already knew. There may not be any salvation this time and no rabbits being pulled from Dr. Elizabeth's magic hat. It appeared that Deb may have used up all her divinely apportioned miracles.

Based on Deb's symptoms, Dr. Elizabeth felt most likely there was a change in her brain tumor and it might be possible for Deb to undergo another stereotactic radiosurgical procedure, aka the Gamma Knife. But she also could not rule out another cause without further testing. Dr. Elizabeth first discussed the option of going back to the hospital to stabilize Deb and initiate further testing.

But this time Deb would not relent as before. She remained adamant about not going back to the hospital due to her profound fear of the place. Dr. Elizabeth then offered to get everything set up so Deb would have express entry into the medical center where she worked early in the morning. First, she would stabilize Deb by tackling her severe dehydration with a sodium chloride IV and as well intravenously deliver stronger doses of anti-nausea and steroid medication. Next, it was vital that Deb undergo another brain MRI, ASAP.

But Dr. Elizabeth offered one last option—literally. I knew based on how quickly Deb's condition was spiraling, this would likely soon be forthwith. But I was still not prepared. After so many years of the war, hearing Dr. Elizabeth finally utter that word was so surreal.

"Hospice!"

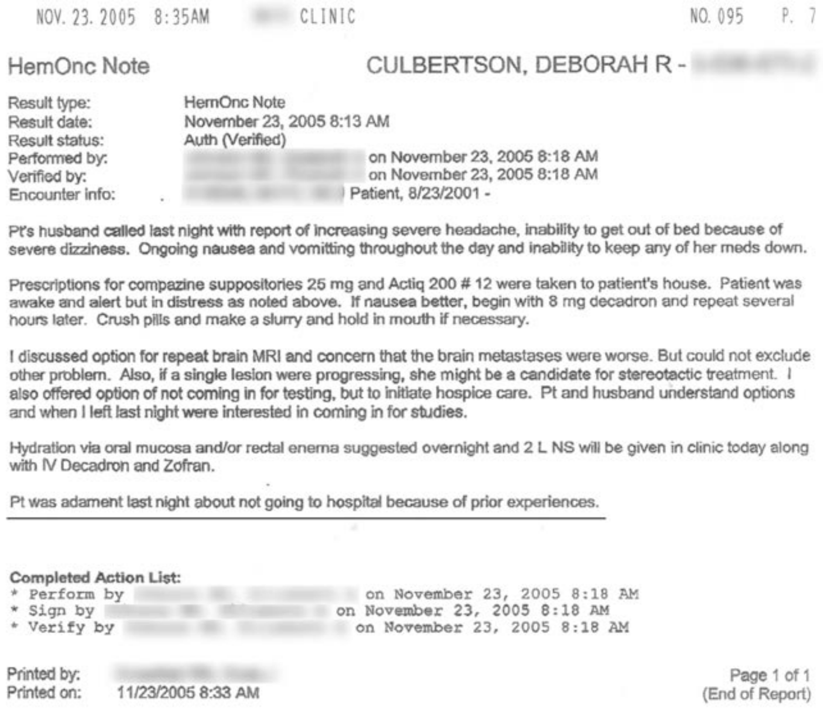
That was an option at the moment too painful for either Deb or me to contemplate. Deb spoke up as I remained speechless.

"Yeah, that's what I want to do. I want to come to see you tomorrow."

To say that I was relieved doesn't come close to the feelings that flowed through me as those words flowed from Deb.

In absence of another ambulance ride to the E/R, Dr. Elizabeth was determined to see Deb through the rest of her night as best as she could until she could see Deb in the morning. It was approaching midnight and Dr. Elizabeth inquired about twenty-four-hour pharmacies around us as she pulled out her prescription pad and started writing scripts for every non-pill form of what Deb needed that she could.

Dr. Elizabeth prescribed a nausea med delivered via a suppository and <u>non-morphine</u> "lozenges" for pain that would be slowly absorbed in Deb's mouth. Deb would be able to get some immediate relief without the benefit of an IV or trying to keep a pill down. It was also critical that we try to get Deb hydrated. Dr. Elizabeth and I discussed my using the enema trick I had to use on Deb several times during her war.



NOV. 23. 2005 8:35AM [redacted] CLINIC NO. 095 P. 7

HemOnc Note CULBERTSON, DEBORAH R - [redacted]

Result type: HemOnc Note
Result date: November 23, 2005 8:13 AM
Result status: Auth (Verified)
Performed by: [redacted] on November 23, 2005 8:18 AM
Verified by: [redacted] on November 23, 2005 8:18 AM
Encounter info: [redacted] Patient, 8/23/2001 -

Pt's husband called last night with report of increasing severe headache, inability to get out of bed because of severe dizziness. Ongoing nausea and vomitting throughout the day and inability to keep any of her meds down.

Prescriptions for compazine suppositories 25 mg and Actiq 200 # 12 were taken to patient's house. Patient was awake and alert but in distress as noted above. If nausea better, begin with 8 mg decadron and repeat several hours later. Crush pills and make a slurry and hold in mouth if necessary.

I discussed option for repeat brain MRI and concern that the brain metastases were worse. But could not exclude other problem. Also, if a single lesion were progressing, she might be a candidate for stereotactic treatment. I also offered option of not coming in for testing, but to initiate hospice care. Pt and husband understand options and when I left last night were interested in coming in for studies.

Hydration via oral mucosa and/or rectal enema suggested overnight and 2 L NS will be given in clinic today along with IV Decadron and Zofran.

Pt was adament last night about not going to hospital because of prior experiences.

Completed Action List:
* Perform by [redacted] on November 23, 2005 8:18 AM
* Sign by [redacted] on November 23, 2005 8:18 AM
* Verify by [redacted] on November 23, 2005 8:18 AM

Printed by: [redacted]
Printed on: 11/23/2005 8:33 AM

Page 1 of 1
(End of Report)

Dr. Elizabeth's note from the 'house call" she made for Deb the last time we would see her. Dr. Elizabeth was unquestionably Deb's guardian angel.

Amazingly, yet not for a physician such as Dr. Elizabeth, she volunteered to stay with Deb while I ran to get the scripts filled and pick up the supplies I needed. With a pharmacy on almost every corner, fortunately, I did not have far to go. When I got back with the prescriptions, Dr. Elizabeth administered the first doses and we discussed my final marching orders. It was now just after midnight and Thanksgiving Eve.

As I walked Dr. Elizabeth out to her car, I kept thanking her every step of the way. Every step of the way she kept telling me, "There's no need to thank me, Walt."

Our last care planning detail before Dr. Elizabeth departed was to verify where the ambulance would deliver Deb at her medical center. As we hugged goodbye, I could not help but continue to thank her once more.

"We'll see you in the morning! I can never thank you enough for all you have done for my wife. So many times. Over and over. Thank you so much for always being there and for your care and caring, Dr. Elizabeth."

Those mere words, still to this day, seem so woefully inadequate in the face of all the care Dr. Elizabeth had rendered over those years. Deb and I were so very blessed and yes—so very deeply thankful for her and most assuredly to her. Dr. Elizabeth is a doer of miracles and an angel of a physician.

I opened her door and hugged her once more, helping her into the car not wanting to take my eyes off her as I closed her car door. I continued to stand there and take in the cooler-than-normal southern evening and watched as Dr. Elizabeth slowly backed out. I walked to the end of our driveway and continued watching until the red embers of her taillights disappeared. Looking back, I suppose I had an eerie feeling and question from deep within. Would this be the last time I would see her? I heard Deb say we would go, but I wondered.

When I went back inside, Deb's pain was starting to ease a touch and her first request was predictable: "Release my Cody-bear from Steven's room."

I waited for her nausea to subside and the suppository to be completely absorbed before turning my next focus to trying to help rehydrate Deb. I warmed some water slightly and added a teaspoon of salt and got Deb ready for the enema procedure. I could tell Deb was starting to feel better even as her room was still spinning from a lack of steroids in her system.

"Here we go again," she mischievously half-laughed. "Somehow, you figured out another way to get my ass in the air, didn't ya? No matter how, you always figure out a way to play with that ass, don't ya?"

After a few minutes of banter and lightly laughing off the tenseness of what I was doing, Deb drew quiet for a long while. I knew she was most probably, as I, locked into thoughts of our conversation with Dr. Elizabeth and consequently, lost in thoughts of mortality. We were well into the procedure when Deb finally broke the silence in typical Deb fashion.

"You still back there and enjoying that view or what? Yeah, I know. Do I finally got a fat ass or what? Yeah, go ahead, keep looking. Never thought you'd see an ass like that on my ass, did ya, Baby?"

All I could do was bust out laughing, which just got Deb laughing enough it interfered with the procedure at hand!

"You better not get to laughing too hard and undoing everything we are trying to do or I'll be back here staring at your ass a helluva lot longer!"

In the middle of so much going on, Superwoman still had her superhuman abilities. In this case, her battlefield humor in the face of challenging circumstances and delicately painful situations. Wielding adroit toughness, Deb made jokes and laughed in the face of what would be kryptonite for others. Deb did not just break the ice but an iceberg of raw emotions—so little seen at the top yet growing ever wider at the bottom.

After tidying Deb up, she said she felt a little better from the combination of the medications. I was ready to finally get as much rest as we could. But I should have known it was not going to be as simple as that. When I reached for Deb's nightstand lamp, she asked me to leave it on for a minute. Immediately I knew Deb was going to jumpstart our morning discussion.

"Pass me that," Deb said, pointing to the stack lying in the seat of my recliner next to her side of the bed. That chair had become my primary office during that torturous year. Have laptop will travel, hospital and waiting rooms included. At first, I thought, oddly for Deb, she was pointing to my laptop.

"No. I don't want no damn Mary, I want my story."

Mary was the name Deb had given every laptop I ever owned over the years. She took to calling them "Mary," because, "that damn thing is in your lap more than I am!"

What Deb wanted was underneath "Mary." It was an early edited draft of a partial manuscript. The birth of what you are reading now. I had begun 2005 lost, angry, and disillusioned with both the system and that Deb's cancer had returned with such a vengeance. With Deb's encouragement, support, and collaboration, therapy of sorts, I started slowly writing a healthcare survival guide. My goal was to share what I learned from decades in healthcare wrapped around

Deb's story and what we learned through the miracles and meltdowns of her journey. All the things we didn't know but had to learn the hard way about Healthcare in America.

Deb's goal was equally altruistic. "I want you to write down my story and get it to Oprah. If Oprah knew what was happening to people like us, she would fix this shit and put a stop to it."

In that moment and puzzled by Deb's request, I handed over the manuscript and started to clear the stack out of my chair to sit down. But Deb motioned me to my side of the bed.

"Come over here with me. Come lay down, Baby."

Deb slightly raised her side of the adjustable bed we had gotten her at the start of her war. She started flipping through the pages of her care miracles and medical meltdowns. The lamp was dimmed and even if it weren't, given her dizziness and blurred vision, I don't think Deb could have read a single word. But she was not trying to. Deb just kept flipping through the pages, sometimes roughly enough I thought she would rip the pages from the spiral-bound book.

Deb was fighting back her tears. I didn't know what to say. I still clearly hear her trembling voice and pained whispering through her heartbreak and tears now starting to flow. The grief-stricken question Deb asked me still torments and obsesses me until this day.

"Hey, Baby. Why does healthcare hurt so bad?"

I failed Deb and our sons that evening. I did not have an explanation. All I had were tears.

"Before you got sick, Baby, I thought I had all the answers. But I don't know why healthcare has to work this way. Why it always seems healthcare hurts so much, trying to get it or trying to pay for it."

Deb reached for my face and I got up on one elbow and looked down into her eyes, still so gloriously blue, yet now painted in a watery red hue.

Crying so hard at times we could barely understand each other, Deb slightly waved the manuscript, clutching it as she stared through me in her pain. Deb told me no more.

"I can't go back to that hospital, Baby, and I know that is where all this shit is headed. If I keep fighting, I'll be leaving you and the boys in worse shape than you already are. You should have divorced me when you had the chance, Baby. You should've."

Deb took my hand in hers and stared into my eyes. "I won't live through any more of this. I can't. I am so tired, Baby. I just can't do this anymore. Is it OK, Baby? Can I just finally rest??"

I could hear myself saying the words. But these were not the thoughts flowing through my mind. From her very first skirmish, Deb turned an expected short battle into this very long war. So many times, Deb was given little hope. In the beginning, she was diagnosed as non-operable and given little time. We seemed to have few options. But all along the way and until that moment, Deb had managed to fend off this final act of care.

"Oh, Baby. Yes. Yes, of course, you can rest, Baby. Anything you want and anytime you want it. Above all else, the boys, Cody-bear, our family and I love you and never, ever want to see you in pain or suffering in any way."

A flood of tears rolled down Deb's cheeks as we eternally locked eyes as we first had so many years before.

"This always has and is your decision, Baby, and we support you in all that you decide. If that is what you want, that is your wish, then God yes, Baby. It is time to rest!"

I slowly moved down closer to Deb and started lightly kissing her. Her lips were salty from all the tears that had flowed down. We kissed again and again, neither one of us wanting to be the one to stop. Deb laid the manuscript down by her side and picked up the "magic remote" to her "magic" bed she so adored. She turned off the lamp and then tried to lower her side of the bed, but hit the wrong button, raising the bottom and jostling Cody about from his appointed spot at her feet.

After a couple failed attempts to get the right button in the dark, I reached for the remote.

"Let me help you lower the bed, Baby."

Even at this moment, at this late hour in both the evening and of her life, Deb was independently determined to do it herself. She was lightly giggling and crying at the same time until she finally hit the right combination on the remote and Cody settled back down. We shared so many laughs in that bed, especially when Cody was much younger. Our surefire way to playfully get Cody off the bed was to turn the vibrator on or raise and lower the bottom of the bed. Deb would laugh so hard. Somewhere along the way, however, damn if Cody didn't get to "liking" that bed vibrating as much as Deb did.

She rolled over still crying and I snuggled up next to her, holding on as closely as I could without hurting her. Over the many months, holding her and spooning had gotten difficult, given so many battlefield wounds. I was determined to never let go of her. I lay there holding her, fighting to stop my tears.

The Other Kind of Care

Finally, the moments of anguish were pierced only by Deb's tears withering away. I listened to her breathing change and then silence as the effects of Dr. Elizabeth's care gained control. There was no pain. Deb's beautiful face was no longer awash in flowing tears. The room was no longer swirling. Though still physically trapped in her bed amid the maelstrom of consequences from her journey, Deb was for the moment free of her confinement within her dreams. There was just the whirling of the ceiling fan overhead. As Deb started to snore lightly, I knew she finally had peace and solitude on that early Thanksgiving Eve.

But for me, there was no peace. The room was now swirling as fast as the blades on the ceiling fan above. As if I were the one on the battlefield fighting with so many powerful foes flanking me on all sides. Replaying again the options Dr. Elizabeth had given us. Replaying again, Deb's words as she initially made the decision to go back, and then later, not. The war was over. But I was not able to confront Deb's decision with the same courage she was.

Reaching around Deb and feeling her hand resting on these cold, hard pages, I was loathing every word I had written. Superwoman's hand was resting on a block of kryptonite that I, however unwittingly, dug up. The good guy in the movie manipulated to do something wicked with unforeseen consequences against their hero. I felt as if the pages had been curled and hardened into a blade and stabbed through my heart.

I did not want to live a final chapter culminating in losing Deb. But I did not want to see her in such pain and tormented agony. None who loved her wanted to see her continue to live in hell. But none who loved her wanted to lose her.

I was very tired, physically and mentally exhausted, but I could not fall asleep. I was now fixated on a compendium composed of miracles, yes, but far more meltdowns. Quietly, and trying not to disturb Deb, I slowly edged out of our bed. I was damned and determined to accomplish my mission. I was steadfastly resolute to destroy that which was haunting me and killing Deb—these words representing her painful journey. There were so many battlefields on so many fronts adding up to one helluva war.

I carefully removed the manuscript from under Deb's hand and carefully inched into my chair next to her bedside. Starting from the title page, I slowly and methodically tried to erase everything that had happened to Deb. As quietly as I could, I ever so slowly started ripping apart each and every page. Top to bottom and left to right. I don't recall how many pages I made it through, perhaps a couple of dozen, when Deb's voice penetrated the silence.

"What are you doing, Baby?"

I put down the manuscript, hoping in the dark Deb could not see what I was doing and she had not been awake too long watching me. But I was wrong on all fronts.

"Is that my story you are ripping up?"

I did not answer because I had none. I did not know what to say to her in the face of my illogical behavior. I knew inside ripping these pages apart was not going to erase anything nor wake us up from our harrowing nightmare. What Deb asked next would slowly rip me apart for the next fourteen years until l finally mustered the courage to fulfill her wishes. To not only live that last chapter with her but to promise to document the moments as we had from the start of the war, until the bitter end.

"You better be able to glue those damn pages back together. I want you to promise me you are going to finish my story no matter what. You are the only one that can tell Oprah and others what happened to me. You need to tell them so they don’t learn the hard way like we did.”

My brain was continuing to spin faster than the ceiling fan, flooded in so many raw emotions.

“I understand what you want, Baby. I do. I promise.”

Deb was right after all. Others had to know. Doctors and nurses had to learn. That was the only way to make change happen. We all have to work together to ask the same question and then stick our head out the window and no longer in the sand, and collectively scream at the top of our lungs:

“I’m mad as hell and I’m not going to take it anymore! Why does healthcare hurt so bad?”

Busted, exhausted, and vanquished, all I could do was crawl back into bed and hope I would fall asleep and awaken from this terrible nightmare. Hoping this wrenching journey was somehow an extended horrendously bad dream.

But with the light, the morning came. I was still trapped inside my nightmare. I called into Dr. Elizabeth’s office and shared what Deb had decided and asked if they could help make the necessary arrangements to begin hospice care. Deb was badly dehydrated, and dangerously low on steroids in her system, making it impossible for her to stand or move. Deb was on a complex regimen of twelve different drugs. While her nausea was better, it still existed enough that even by morning she could barely hold down a cracker or two, much less anything else.

An oxymoron of sorts, we would first have to get Deb well enough for her to be able to have the kind of hospice care that she wanted and where she wanted it—in our home. The first step was to get Deb stabilized at a hospice care facility. This time Deb voluntarily got into the back of an ambulance. She couldn’t take any more of the pain in her head and the room spinning along with her stomach. She knew we could not otherwise get her out of the house and over to the hospital where the hospice wing was located any other way. On Thanksgiving Eve, once more, our local EMTs did a masterful job getting Deb around the alcove and out of the bedroom and over to the hospital hospice facility downtown.

Deb was quickly admitted and placed into her own room on the hospice floor. Not long after arriving, we got to meet Dr. Paul, who would be in charge of Deb's hospice care ongoing. He was a shepherd among physicians and quickly made both Deb and me feel at ease with his skill, bigheartedness, and caring. From the very first phone call with our community hospice organization, they were empathetic, compassionate, and worked swiftly to get Deb admitted despite initial complications obtaining the required preauthorization from our insurance company. Push came to shove, and even before we could obtain the "pre-authorization," we had no choice, regardless of what the insurance said or not, we had to admit Deb into the facility, given her condition.

Straight away, Deb made herself crystal clear to Dr. Paul. She <u>was not</u> staying in that hospital or any facility one minute longer than she had to. She wanted to go home as quickly as she could, and that was the only way she would be concluding her story. Warmly, Dr. Paul spent a good bit of time talking to Deb and me about what we could be in for with Deb's condition and being at home and wanted to make certain that both of us knew what we were asking and what the road ahead would likely entail.

Dr. Paul also made clear that we would have the full support and assistance from his staff working collaboratively with us as part of Deb's home-care team. They would always be a phone call away. As the hospital staff worked to get Deb settled and stable, I made the round of calls to our family. Jeanne, of course, was my first outreach.

"Mom, I am so, so sorry to share this, but Deb has decided enough of the battle was enough. Dr. Elizabeth had to make a house call last night because things got so bad. She was able to stabilize Deb enough to make it through the night, and this morning we had her transported to the hospice facility here at the hospital downtown."

Mom was not surprised by the news. We communicated very frequently and she was fully in the loop of what was happening with her daughter. Unquestionably, especially given all she herself had lived, Mom was better prepared than me. She embodied the steely outcomes of that old adage, "What doesn't kill ya…makes ya stronger."

"I am so, so sorry, son," she said. "I have known this was coming and wondering how much more hell Deb was going to be able to take. Please know how much Dad and I love you and stay strong. We're on the way!"

As Deb started to get intravenously delivered versions of her pain, steroid, and nausea medications, along with fluids to rehydrate her, she quickly started to rebound and was able to better take some of her other meds. Just as quickly, especially given the over four-hour distance between us, Jeanne and Ken arrived. Not long thereafter, Deb's beloved Aunt Shirl, who lived six hours away, walked in. With all of them there and gathered about Deb, they urged me to go home, grab a shower, and get some rest, I am certain, looking at the disheveled mess I was.

I knew rest, if even then, would not come until I got back to the hospital to camp out for the night with Deb. However, a shower and a conversation with my sons were well in order. While we did not know how long Deb would be in the hospital hospice wing, without question she would be there the next day, Thanksgiving. As Deb and I had discussed it earlier that afternoon, even before our guest list grew, Deb had already commanded, "The turkey show must go on!"

Weary, tired, and looking like hell, I still stopped by the local grocery store. I did a quick shop-and-go for last-minute items for our houseguests and to finish putting a wrap on the accompaniments for the annual extra-large turkey that had been thawing in the fridge since the weekend. But for this Thanksgiving Eve night with my sons, we would be feasting on Chinese from the take-out, all too conveniently located next to the grocery store.

With arms full of bags and Chinese, I fended off Cody, who mobbed me at the front door until I finally had to order him to his place. Since he was a little puppy, Cody sadly had witnessed Deb's comings and goings too many times. He did not like it when Deb was not in the house, becoming very sad and "very needy!" It is hard to visualize unless you have ever had such an in-tune furry family member, but Cody didn't just mope about whenever Deb was gone. He "mooooooped" about! The boys and I always made certain to give him lots of extra attention including his favorites, Frisbee sessions, ball in the backyard, and long evening walks that were therapeutic for all taking part. But he was not himself until Deb was back home.

With Cody and my shower tended to, and all the extra bedding out and everything ready for our houseguests, it was time for my most agonizing heartful task. While our sons plainly knew their mom went back to the hospital that morning, they did not yet know the full extent of the decisions she had made late into the night before.

We peeled open the Chinese at the nook where we most often had our meals. The nook was located just off an open kitchen and a large open living room. With a simple head swivel, Deb could sit in her recliner-rocker and easily view her large-screen TV, the aquarium, and the goings-on in the kitchen. To the left, there was a wall of tall windows overlooking the backyard and conservation area beyond our fence.

The aquarium was behind the nook table against much of the back wall. It was a large, narrow, custom-made acrylic saltwater aquarium. We got it when we moved there as therapy, at the suggestion of one of Deb's medical team. Deb had spent hours upon hours fish-gazing. Over the past years, I had witnessed so many tears turned into smiles and calm as Deb stared fixedly into that tank. It was indeed magically therapeutic.

Of all the fish in the aquarium, the one that most captivated Deb's heart, and I suppose all who met her, was "Puffy." Does not take much imagination to figure out she was a Pufferfish. To be certain, Deb had collected all of Puffy's pals including Dory the Blue Tang, Nemo the Clownfish, Bubbles the Yellow Tang, Tad the Yellow Longnose Butterflyfish, and Gill the Angelfish, among others. But blue-eyed Puffy was everyone's favorite. While her sex was not determined by science, or nature, for that matter, she was accordingly labeled by Deb.

"Yeah, the way that little slut is batting those blue eyes at ya when you get near her, that's gotta be a damn girl!"

Over time, I trained Puffy to let me pet her. Crazy as it sounds, both in action, given how highly poisonous they are, and in feeling, as we are after all talking about a fish here, but Puffy loved to be petted. Deb got the cutest giggle watching me pet her and getting her to do the "Shamu-wave" back and forth across the top of the tank.

But the other reason Deb was so closely taken with Puffy was that she so identified with that fish. She often said Puffy reminded her of herself. Puffy had lived through hell and back during our saltwater learning curve as one of the first fish in the tank. So many times, we feared and fretted that we had lost her when all the other fish around her died. But as with Deb, Puffy took the proverbial licking and kept on ticking. The first aquarium company yielded constant problems, a green tank, and many lost fish. But through it all, Puffy survived.

We fortunately next found Joe, who was highly skilled and experienced. Over the years of taking care of our tank, Joe became a good friend and warmly connected to Deb's plight. We always looked forward to Joe's visits and chats over the phone with his wife, Pam. Joe never minded that Deb talked his ear off while he was attending to the tank. We were grateful for their compassion. Joe was there over those difficult years and witnessed firsthand inside our home, Deb's evolution and sadly, what was happening with her. Among the warmest hugs I received were always those from Joe.

Normally when their mom's seat at the nook table was empty, it would be a quiet dinner staring at Deb's aquarium with Puffy doing her thing and stirring up Dory and Bubbles. But on that early evening, it was difficult to keep my head up. When I did, I could not stop staring at Puffy, who was staring back at me. Looking at those crystal blue eyes and thinking of Deb as my heart sank. I had a lot to share. Yes, much the same type of conversation we had to have several times before, including our journey back from New Orleans a few years before. But this time, unlike before, there would be no magical miracle cancer pill swooping in to save the day, or at least prolong the inevitable. The inevitable had arrived.

Thomas and Steven asked a lot of questions, some of which I felt I had not had the best "Ward Cleaver or Steve Douglas" philosophically artful monologues.

"If Mom's not going to have any more treatment, how is she going to get any better?"

"Is Mom just going to keep getting sicker and sicker?"

"Does this mean Mom is gonna die?"

That was the one question my sons asked of me, and the one I just could not bring myself to address with an answer, much less a *Father Knows Best* delivery. But as I looked into their eyes and them into mine, it was clear they had asked a question they already knew the answer to. It was difficult to move away from the table to get ready to go back to the hospital. Much of what I remember after their initial difficult questions was that group hug we had. It was a very solemn drive back downtown to the hospital hospice wing.

As I rejoined Mom, Dad, and Aunt Shirl in Deb's room, visually I was not the same disheveled mess I was when I left. But on the inside, I was worse than a disheveled mess. I suppose there was no fooling Mom or Aunt Shirl. Mom kept Deb distracted while Aunt Shirl motioned me outside. We stepped over to the family lounge nearby. The first thing Aunt Shirl did was give me a long, warm hug and thank me for all I was doing and had done for her niece. She shared that all in the family were so very proud of the boys and me and how we had gotten on over so many years during one battle after the next in Deb's very long war and journey.

Many years of nursing taught Aunt Shirl when it comes to patient care, even the brightest of exteriors may still be dark within. She asked me how I was doing and hanging in there and we talked about the boys. I shared with her the gargantuanly heartbreaking conversation I just had with Steven and Thomas. As I spoke, it was difficult to keep from breaking down right into Aunt Shirl's shoulder in the middle of that very public area. But Deb was the only one that had seen my tears and I was determined to keep it that way. I had to remain resolute and strong. I had to maintain an unruffled facade regardless of what was germinating below the surface.

While Aunt Shirl almost inadvertently triggered my coming unglued, in feeling her warmth and the family love wrap around me, I found strength and determination. As with her older sister Jeanne, their great caring, courage, and ability to maintain calm about them within the storm, inspired me to steadfastly maintain my resolve and ability to do the same. Above all else, I had to do so for Deb and most especially, our sons. When we went back into Deb's room, we made the big Turkey-day game plan. While I assumed my normal "Deb in the hospital" position, camping out alongside her, the rest would stop somewhere on the way over to our place and grab dinner that night.

With our Turkey-day game plan set for the next day, they departed. I got comfortable in the large recliner-chair that I pulled as close to Deb's bedside as I could. Over the next few hours, we attempted to come to grips with where we had arrived in Deb's very long journey. We talked about the curves we encountered and the people we met along the way. But we mostly focused on our sons. With them in our hearts, we discussed what Sue had shared in wanting to shield her son Jason from witnessing her journey down the highway and up the mountainside, continuing into the blue sky above.

Our sons had lived hell on earth. But instead of crumbling, they wielded the devil's flame burning all about them and forged a suit of unbreakable and seemingly impenetrable armor. Over all those years, they never missed a beat. They had maintained their focus on their schoolwork and assisting us with the housework. They never once got in trouble inside or outside our home nor in any other way drifted off course, even in the middle of a hurricane. They had been our shipmates on this voyage all along. We determined they had the strength and mettle to make this final passage.

The more the evening wore on, the more all the medications Deb was receiving demonstrated a great effect. The steroids were truly remarkable despite all the complications and side effects they caused. Deb became more lucid and talkative. Combined with her pain and anti-nausea medications, the real Deb was swiftly reemerging. So much so, she wanted to stand up out of bed "and get off my fat ass" for the first time in over a week.

It was all I could do to verbally restrain Deb while trying to convince her to do this the right way the first time, with the assistance of her nurse and a walker.

"I know you're Superwoman and you're ready to fly, but let's take a baby step before you try to jump off the building!"

It was late and as is typical even in a wonderful and caring hospice facility, there was less staff working the night shift. Deb was impatient as it was taking a few minutes to get someone to come in. As I learned many years before, when Deb got her Dutch determination rolling, not even a powerful locomotive stood a chance of slowing her down, much less stopping her.

I had already dropped her bedrail on my side of her bed earlier when I positioned my recliner next to her. Before I could lob another protest, Deb sat up and exasperatedly swung her legs over the side of the bed with that "Deb determined" look on her face.

"Move that chair out of the way and come here."

I knew one way or the other she was going, so I moved the chair and positioned myself in front of Deb, bending over as she wrapped her arms tightly around my neck. Carefully and as cautiously as Deb being in a hurry would allow, I helped her rise up onto her feet. Like a sailor standing on dry land for the first time after an extended voyage, Deb was wobbly and unsteady at first. With her arms still wrapped tightly around my neck, she started to lightly kiss me repeatedly as she giggled. Deb was very pleased with herself and her accomplishment.

"See, I told ya! I don't need a walker. I got a Walter."

I had not heard Deb, or for that matter, anyone, call me Walter in decades. We held on to each other, busting out laughing. I am certain we made for one interesting sight when the nurse did walk in on us.

Smiling, she inquired, "And just what do we have goin' on up in here?"

Deb did not miss a beat, tuning her head to the nurse and immediately responding, "Yeah, we tried doing this shit in the hallway, but someone told us to get a room and this was the only one we could find."

I thought that the poor nurse was going to fall on the floor. Now, all three of us were hysterically laughing.

"Well, you sure look like you're in good hands there, Mrs. Culbertson, is there anything else I can help you with?"

Deb thought about it and decided there was one thing she wanted to accomplish on our own. "I wouldn't mind ditching that damn bedpan. Can we make a trip to the potty?"

Deb's nurse that evening was adorable, heartful, and kind. While agreeable to Deb's request, she insisted on making the short round trip to the bathroom using a walker, despite Deb continuing to protest that she had a "Walter." Afterward, as the nurse was helping Deb back in bed, making certain she had everything she needed, Deb had one more declaration.

"I know y'all like to come and go all hours of the night, but I really want to get some sleep tonight, so can you knock that stuff off? And besides, my husband is going to be sleeping with me in the bed tonight, so you never know." She winked at the nurse.

Confounded, yet as many times during my life with Deb, not shocked, I looked at Deb, back over at the nurse, and down at that tiny bed.

"I don't think we can both fit in that bed together, Baby. Plus, you do need to get some rest tonight and I'll be right here in the chair next to you!"

But Deb was serious. "Nope! Your ass is going to be right down here next to my ass tonight!"

I looked in the direction of the nurse openmouthed, completely expecting she would back me up as a care-ally, certain she would replay, as past nurses had, all the reasons why my ass could not be down there in that bed next to Deb's ass as she wished. But, no, not this nurse!

"Oh yeah, honey! I think you two can fit in there just fine. Trust me, it's been done before, I'll get y'all some extra bedding."

I couldn't believe what I was hearing. Over the years, I admittedly did crawl in the hospital bed next to Deb to comfort her, but the nurses were never happy about such activity in those days. Now Deb had a nurse collaborator. She happily brought us the extra bedding and helped position Deb to the side of the bed that had the rail up. With the hugest, warmest grin on her face, the nurse made her way to the door and the light switch, turning to look directly at me as she said, "What happens in Vegas, stays in Vegas, Baby. That's all I'm saying!"

Deb loved it. She had a nurse cut from her own cloth. It was wonderful, warming, and inspiring to hear Deb laugh, especially in the middle of such a Twilight Zone-ish dark storm. But I was still looking down at that bed and the little sliver of empty space left, wondering. The last time I attempted this bed maneuver, Deb was skin and bones. Now she was quite larger. I wasn't quite certain how this was going to go. How much of my ass would be hanging off that bed?

It certainly was a snug fit, drawing us all the closer together for pillow talk far different from any in our twenty-three years together. On that evening, there were no tears. Just remembrances flashing before us of the life we had shared together. Lying in the dark on a crowded hospital bed busting at the seams, machines whirling, we relived the many good days, the sometimes bad, the few ugly, but mostly the blessed moments of our life together.

As I had many nights before, I half-drifted off to the sound of Deb peacefully sleeping once more. It was difficult to solidly sleep even though I was dog tired. I awoke early the next morning to the light of the sunrise shimmering through the hospital window and bouncing off the asphalt rooftop of a lower adjoining building. Once again, I eased out of bed doing all I could to keep from disturbing Deb and waking her from her slumber.

I ran into Deb's new morning nurse I had seen peek in our room earlier on my cafeteria coffee run. She laughingly shared she had checked in on us several times when she came on shift. Deb was so soundly sleeping. At the suggestion of our compassionate nightshift nurse, she just let us stay snuggled rather than disturbing Deb during her normal morning rounds. This was indeed an altogether different hospital experience than any in the past, I suppose befitting the realities of the destination Deb's journey had carried us to.

Our T-Day plan worked perfectly. As Mom, Dad, and Aunt Shirl arrived, Deb was just waking and I departed on my Thanksgiving mission. During the drive home, I got it in my head from that moment forward and all days in between and until our final parting, I would work to make each hour of each day the most special I could.

As typical, Cody had his "biscuit-butt" parked at the door when I strolled in. Regardless of what else I had planned, Cody's plan was to get all the attention he could. After a stroll into the back yard with the Frisbee, I threw together the stuffing and got that "big-ass bird," as Deb referred to it, in the oven as quickly as I could for the six-plus hours it needed to cook. Then it was showtime. That is, for our other annual show. To their initial chagrin, I surprised Steven and Thomas with their mom's proclamation we would be adhering to.

"The Turkey-Day show must go on!"

Unquestionably, they did not see this coming with their mom in the hospital. Perish the thought. They would not be getting this

Thanksgiving Day off after all. Ugh! But they got into the spirit and specialness of the effort as we started engaging in our annual tradition of getting up in the attic and bringing down all the Christmas decorations and starting to set them up. While we couldn't accomplish most of the outside mission in a day as we normally did, working dust to dawn with their mom addressing the turkey, we could at least get a hell of a jump. Our collective goal was to have our home fully lit up and "Clark-Griswold-sized" to the max by the time their mom was discharged.

After making the Thanksgiving meal, I put together a special to-go package, leaving everything wrapped and ready for the others when they were ready to eat. Working on our mission to make everything phenomenal for their mom, Thomas and Steven went back with me to the hospital to surprise their mom for Thanksgiving. Debbie was very pleased to see Thomas and Steven walking in her room, as were their grandparents and Aunt Shirl. It was not a long visit with turkey dinner waiting for them all at home, but it most certainly was very warm. Deb was deeply touched. After everyone departed, she shared how much that meant to her being able to see her boys.

I used the microwave in the staff lounge to get the gravy piping hot and got everything ready for our special Thanksgiving meal. Deb wanted to sit up on the side of her bed. I laid out a lacy tablecloth on her little adjustable bed table and set up our meal, wineglasses of water included. Deb was still a little dizzy and working on getting her appetite back and keeping things down. So I don't recall that she even ate much of her meal. But I do vividly remember that imperishable Thanksgiving, seated across from the most beautiful, special, and courageous mother and wife.

The Enemy at the Gate

After a replay of our cramped maneuvers from the evening before, I carefully eased out of bed to start day #3 on the hospice wing of the hospital. Just in time for our mettle to be tested again—on the other side of healthcare. Deb overheard an inadvertent conversation that the authorization from our insurance company still had not yet been received for her stay. I attempted to console Deb with the knowledge that at least the health plan did not just flat out deny us yet. For the umpteenth time, I leveled my oft-used refrain.

"Well, Babe, you know how long insurance companies take!"

But Deb's financial concerns added to her already headstrong desire to depart the facility as quickly as she could from the moment we arrived. Now she wanted to get out of Dodge even faster than her care team wanted her to. When Dr. Paul cruised into Deb's room for his morning rounds, Mom and Dad had just arrived and all we could do was silently listen in dismay as Deb pressed Dr. Paul hard to be released.

While he agreed Deb had made great progress in two days, clearly, he did not think she was ready to go home, especially as she was not fully on pills instead of IVs yet. But Deb continued to challenge him. Finally, Dr. Paul relented and made Deb a deal. If she could across the board switch to pills for all her meds, while also eating "all" her meals and holding it all down for the rest of the day and through Saturday, he would consider releasing her over the weekend.

While Mom and Dad spent the afternoon with Deb as Aunt Shirl prepared to leave, I went back to the home front. I alternated between my insurance company outreach and continuing to make as much progress as I could on the Christmas decorations, especially cognizant of Deb's likely expedited hospital departure, given she was "Deb-determined!"

The long and short of all the time waiting on hold and being passed around between customer service reps and the manager I at one point demanded to be connected with, was predictable. They were still trying to obtain and/or process the requested additional information and records from Deb's oncologist and her recommendation and justification for hospice care. As few Americans are aware, but I saw in gory detail working from inside the gates of insurance companies for so many years, there is enormous complexity within the costly bowels and internal processes of health plans.

Infuriating now that I was on the patient end of the health transaction, I knew had Deb been going back to the previous hospital affiliated with the medical center, there would have been fewer obstacles and barriers, especially as we were already decreed out of network there, one of the reasons Deb did not want to go back, in addition to her fear of the place. But in this health transaction, Deb was being admitted to a new hospital facility, to be treated by a new medical provider and for a different primary diagnosis: "hospice care intervention" rather than "continuation of cancer care intervention."

On the late afternoon of day #3 of Deb's new battle in a war headed to finality, I arrived back at the hospice wing of the hospital battle-weary. At times in Deb journey such as this, I sometimes questioned whether ignorance was bliss or knowing as much as I knew about the innards of healthcare was a curse.

You can see something coming for miles and yet you are still powerless to change course. You're on the deck of the Titanic headed for an iceberg and all you can do is listen to the violins playing in the background as you crash into it. But then on reflection and further inspection of Deb's war looking back, I suppose I was able at times to somewhat increase our odds standing at the great American Healthcare Roulette Table.

A shifting of the odds was evident that afternoon as I walked in Deb's room and found her sitting in the chair talking to her parents. Deb's smile dissolved, at that moment, all my other anxieties of that day. I was not at all surprised Superwoman was able to keep pace with the requirements for her weekend parole. Nothing was going to dissuade her from hopping over another building.

Deb was insistent, as with nights #1 and #2, that #3 would be spent the same exact way, "My ass laying down there next to her ass!"

That evening our pillow talk was not about our life but that of her childhood and early life. Deb talked about some of what she had previously shared, only in more detail. But also other things she had never shared, especially memories of her father, Ray, whom she named her first son after.

Deb talked about being very close to her father, one of the reasons that her mother at times sent her to live with relatives during her father's illness. She was still deeply hurt and at times still held resentment. But it was not until Deb herself got sick and saw what it was doing to her own sons that she better understood. Those memories were why she was so terrified of not just what the process was doing to her, but what it was now doing to her family, just as it had her family back then.

Deb told me many more things about her early adult life and in more detail about what it was like getting married and divorced so young, then losing Ray for so long. She talked about how happy she was Ray found Susan. She shared her deep regret after she and Ray reunited that "distance and other things" prevented them from getting closer over the years. She spoke of Thomas and Steven and her great pride. Fueled by steroids, Deb bounced around from one subject or story to the next until she finally dozed off mid-sentence.

Too many nights to count of erratic half-sleep was starting to catch up with even this night owl, but not Deb. With steroids raging in her once again, her headaches dramatically reduced to a dull roar, her nausea gone, very early the next morning Deb arose to Day #4 of her hospice stay bright-eyed and bushy-tailed. She was a woman on a mission.

"I'm gettin' the hell out of here!"

From the very first unlucky nurse to poke her head in Deb's door that Saturday morning until the last in the late afternoon with Deb's parole papers, I felt for each. While Deb could be persistent, the "real" Deb was very polite about it in a charming way. While the steroids greatly benefited Deb, they also greatly impacted her in more confounding ways, as was unfolding that day in the hospital.

Deb was not patient with the fact this departure would be unlike others in the past. It wasn't only what needed to happen at the hospital to discharge her, but what the hospice organization had to have ready on their end to take over Deb's care once she was home. Deb's very kind nurse who had also been with us the day before had taken point on getting discharge clearance from Dr. Paul based on Deb's progress.

She heartfeltly shared, "We understand this drill well and we don't take any of your wife's feistiness personally."

The nurse then made certain I knew how to get in touch with the hospice team over the rest of the weekend. She hugged me warmly and whispered, in parting, what was to be.

"Put your tray table and seatback in their upright and locked position, honey. This is going to be a bumpy ride. But you and your wife's mom and dad appear strong. I know y'all will see her through what's ahead and she'll arrive at a better place."

Unquestionably, my sons and I were already living some of that bumpy ride part. But I was very comforted by her appraisal, as I was eternally grateful having my other Mom and Dad.

Days That Went Quickly Not Quickly Lived

Deb was very surprised and pleased to see the lawn ornaments in the front yard as we pulled into the driveway. Her happiness walking in the front door only equaled that of her Cody-bear. While Cody was oft-spoiled, he was still well trained, including how to greet people at the front door and not jump up on anyone uninvited. But he was so excited to see Deb, the big moose almost knocked her off balance by rubbing himself against her so hard. Deb loved his attention and her laughter echoing through the foyer was music to the ears of all.

It was a very peaceful Saturday evening and Sunday and everything went well. A trait of Jeanne's when there's a lot going on in her world, which Deb greatly inherited, Mom keeps herself very busy, especially cleaning, or in this case, interior Christmas illumination. With Dad's help on the outside, Sunday evening we gave Deb a glorious "Christmas Vacation - Clark Griswold" extravaganza inside and out. For decades, Deb collected angels, and she relished seeing them all about the house and her special life-sized angel that lit up our entranceway, greeting all. As in the movie, we all stood in the yard in various stages of nightly dress, hugging and taking in the splendor of it all.

Early Monday morning, complimenting us on the amazing menagerie of Christmas lawn ornaments, Nurse Nancy from the hospice team cheerfully arrived at our front door. She was the lead nurse and case manager assigned to Deb's care. From the moment we met her, all of us felt instantly at ease. Shorter and stout, she had a wonderful laugh and was warmly empathetic with an angel-of-mercy kind of glow about her. She spent a great deal of time with us that morning and made certain to engage Mom and Dad in the discussion along with Deb and me.

As we reviewed Deb's list of the dozen meds that Deb was on, Nurse Nancy was surprised and impressed that we had organized everything electronically including Deb's daily med schedule into spreadsheets I maintained on my laptop. She quickly figured out I was a healthcare nerd and one of those HIPAA—crats. She and I would have many sidebar educational sessions regarding misguided misunderstanding of the law.

Despite at times insurmountable obstacles, which our rights under HIPAA to obtain our own health records <u>did not</u> make any easier as intended, I had always tried to collect and maintain as many of Deb's medical records as I could get my hands on. Nurse Nancy was well pleased with Deb's personal health record treasure trove and asked a lot of questions while she scanned it, even asking me if I could make copies of a few of the pages I had collected.

The last step after Nurse Nancy gave Deb her initial home exam was to make certain there was no other equipment that hospice needed to order, including furniture. Again, we surprised Nurse Nancy. From a complete medical kit to wheelchair to a walker to a bed-table to even a patient bedside porta-potty, we had already pretty much collected it all over the years of the war. Deb even proudly showed off her fancy bed with the fancy remote. Nurse Nancy and Deb, with Cody along for the ride, made for one hell of a hilarious sight, as Deb put her adjustable bed through all its head and foot, up and down, and all-around vibrating paces.

The game plan Nurse Nancy laid out, in summary, was the hospice team would always be on standby and had a hotline with access to a medical team for questions or the determination that an immediate house call or other escalation needed to be made. They would only plan based on Deb's progress and the approval of our insurance, to initially schedule one visit per week, increasing as Deb's case progressed. They thankfully would also be completely replacing pharmacy runs and the continuing challenges with our insurance at the pharmacy. All the medications Deb needed would now be most often delivered by courier or if needed, by one of the nursing team coming out to attend to Deb.

Sadly, but so well understood, Dad had to get back to work. Ken had a very demanding career with Walgreens, as did Jeanne. They were both mates and work partners as the traveling dynamic duo, helping them put up pharmacies all over the nation. Even still and as always, Mom made it clear she intended to be able to stay as long as her daughter needed her and wanted her assistance. But early in the week, they departed. It meant the world of support and love having Ken and Jeanne there. I was solemn and sadder than ever to see them go.

Over the next two weeks, Deb would start to slide backward and get progressively worse. Now, not just more intense headaches, but more pain in her fingers, toes, and increasing pain in her joints, knees, and her right shoulder where the RFA lung tumor procedure was performed. Several times, including a few evenings, I had to dial Hospice 911. In addition to Nurse Nancy, we also had visits from Nurses Tamika, John, and Rose. Each was wonderful and caring. Everyone worked diligently to assist Deb and provide the best care possible, given the circumstances and Deb's progression.

Joining Dr. Paul, Deb now had a pain management specialist, Dr. Neer, assigned to her care. He was conscientious and compassionate, many times getting on the phone himself to speak with me, or the hospice nurse that was working at Deb's bedside. Throughout the month of December, Dr. Neer would continually make dynamic adjustments to all of Deb's medications. WHY couldn't the drug skirmish battles we had for five years have instead worked this way?

Saturday, December 10, was the day Deb had been awaiting for weeks. Her five-years-younger baby sister, Laurie, arrived from Kansas for a seven-day visit. Jeanne had four daughters. Sandy is a year older than Deb, then Vicky, three years younger than Deb. As Deb and I had for many years, Vicky lived in the same area as Ken and Jeanne. She was a big part of our lives and the boys' as they were growing up.

But Deb's youngest sister, Laurie, was married to Jerry, an army officer. She was perpetually away and had missed all those special family times. Deb and Laurie were close their entire life, physically separated or not. Deb always blamed herself for their distance, or actually, she blamed me! Laurie met Jerry up north when she was up there working with us in our medical practice management business.

Living the always-moving military lifestyle, Laurie had been in her way blessed and shielded by distance from witnessing much of her sister's plight. As with her nephew Ray, it was one thing for Laurie to hear it over the phone. It was altogether different staring it bluntly in the face. If not for looking into Deb's beautiful blue eyes, Laurie likely could have passed her sister on the street and not recognized her. Helping ease the painful reintroduction, Laurie arrived on one of Deb's good days. In between sisterly camaraderie and some laughter the rest of that first day, Laurie helped Deb set up her last special box of decorations containing more of Deb's cherished angels and Victorian figurines.

The next day, Laurie's visit would continue with a bang—literally! Until Laurie arrived, I was only able to escape the house for short trips to the grocery store with the boys' help. But with Laurie there to be with Deb, I could finally get some Christmas shopping done. With the boys in tow, we absconded to the mall.

We were well into our shopping spree when I must've walked into the right area of one of the stores in the mall. I suddenly regained the signal on my mobile phone, as they were called in those days, and the Bing-Bing-Bing alert of my phone went off. I had a string of missed calls and several voice messages from Deb's sister Vicky. I played the most recent voicemail and heard a Vicky greatly panicked and frantically asking me to call her back immediately.

"Something happened to Deb!"

I tried calling Vicky back but could not make a solid connection inside the mall. We dropped whatever it was we were purchasing in that store, grabbed our other bags, and immediately hightailed our way toward the mall central walkway. The boys and I scurried around and through the crowd trying to get to the nearest exit by our parking section. Nothing about Vicky's voicemail made sense, I repeatedly asserted to the boys. "I don't understand why it was Vicky calling instead of Laurie. How could Vicky know something was wrong with your mom when it was Laurie back at our home with her?"

If ever there was a time I was again thankful for technology, it was standing in that parking lot and getting Vicky on the mobile. She distraughtly shared that she and her mom were on the phone talking to Laurie and they heard Deb say in the background, "I'm not feeling well," just as they heard a very loud bang or crash. Then the phone went dead. Vicky said they tried repeatedly to call Laurie back but no one picked up on the house line. They then tried Laurie's mobile phone as well as my office line to no avail. Vicky and Jeanne were panicked. They had surmised that Deb had fallen, passed out, or worse.

Now I was panicked. As soon as I hung up with Vicky, I replayed her steps. I tried our house line, my office line, and Laurie's phone. Just as Vicky described, all just rang. I tried calling our neighbors Dave and Stacy next door but no one picked up. Now both my brain and my feet were racing to the back of the parking lot with the boys trailing behind, struggling with their arms full. Everywhere there were lines of cars trying to either enter or exit the mall. I kept cursing the traffic while glancing at the time on my phone and hoping it would ring and be Laurie.

We finally made our way onto the main thoroughfare and were sitting in heavy traffic in a long line. Only a handful of cars could clear each change of the light at the major intersection ahead. We rolled forward and rolled to a stop, keeping in rhythmic pace and distance with the cars in line ahead of us. During one of those maneuvers as we came to a stop, we suddenly lurched forward to the sound of a loud bang. The vehicle behind us failed to stop. In the grossest of understatements, there is never a good time to get rear-ended. But to have it occur at that precise moment, as I was desperately trying to get home, was worse than finding myself in another horrifying episode of *The Twilight Zone.*

Straight out of a storyline befitting a Rod Serling script and narration, we pulled over to the grass medium with the other vehicle. I was stunned into momentary speechlessness when the driver behind us turned out to be none other than one of Thomas and Steven's friends from high school and his girlfriend, whom the boys also knew. Frenzied, mad as hell, and not thinking straight as I prepared to dial 911, I interrogated the boys' friend. He profusely apologized and quickly admitted he had his mind more on his girlfriend's leg cuddled next to him rather than the steering wheel, brake, or car in front of him. Mine.

I stood there wrapped in the years and recent months of mental anguish, thinking about Deb and looking at the bumper of our still-almost-new SUV. It was all I could do to keep from totally losing it right there on the side of the road in front of my sons, their friends, and all those stuck in traffic. I would love to have heard the audio of the conversation with the 911 operator. I was desperately struggling to calmly get out such complex details in as few words as possible, an already notoriously insurmountable task for me. So I am certain my mouth was galloping faster than my brain and heart, especially when the operator had challenges because I was standing in one county but lived in the next county over.

After an extended delay, we finally started to make the turn into our subdivision and here they came. First in line were not one, but two large fire engines. In passing them, I saw the first truck was from the normal station that frequented our home during Deb's EMT adventures. Deb was always upset and embarrassed that truck was usually dispatched with the ambulance. No matter how many times I tried to explain to her why they respond that way, this was one of the reasons she hated for me to call 911. But the second truck I passed was clearly adorned with the name of the fire station just over a bridge in the other county where I made the 911 call. After that came a fire command vehicle or supervisor, followed by a county sheriff. All were from the next county over.

As I arrived closer to the end of the cul-de-sac near our home, there were two fire station big-box ambulances and two local county sheriff vehicles spread about and around my property. I had to park a little distance from our home because we could not get through the street. The boys and I hurriedly walked up to the house, and the first thing I noticed was while one of the ambulances was our frequent flyer EMTs, the second was from the same county fire station as the fire truck that just left. It was obvious the 911 operator did more than just keep her promise to get help. She called everyone but the U.S. Army and National Guard.

A sheriff's deputy was standing outside our door and I identified myself as the husband and the boys and I made our way in. Deb was seated in her chair surrounded by a crowded sea of uniforms. She was crying and they appeared to be calming her down as they gave way and let me make my way to her. I recognized the one EMT who was just removing a blood pressure cuff and shared with me that Deb was OK, just badly shaken up.

That afternoon of collective adventures, anxiety, and tears, all came to be in the domino aftermath of the loud bang of a blown transformer, a power outage that hit the neighborhood just as Laurie was on the phone with her mom and sister. Debbie, either startled or having a hard time gripping with the pain in her hands, dropped something in the kitchen just as the phone went dead. As it was a warm December with no power in the house, the girls simply went out back to our screened porch, taking Cody with them.

Outside with the door closed, they could not hear the ring of the manual phone we kept plugged in within reach of Deb's bedside. Large with big red buttons, Deb had nicknamed it her bat-phone. It was to be used in emergencies such as this very scenario, losing power and our cordless phones with it. Laurie had left her mobile phone charging upstairs in the guest bedroom so she did not hear that ringing off the hook either.

As an amassing of emergency response teams from two different counties gathered outside our front door, Deb, having one of her better days, was merrily in deep sisterly discussions on the back porch with Laurie, not hearing any of the loud banging on the front door or not recognizing it for what it was.

Finally, and luckily, the girls went back inside. Laurie saw all the shadows and people milling about our outside foyer through the etched-glass front door. In a "WTF" moment, she and Deb walked to the entranceway. Startled and not thinking straight or about her present condition or appearance, Deb herself opened the door just in time. A very big fireman was in the process of just starting to take a very big swing with a very big battering ram aimed squarely at our front door.

Cody, excited by all the commotion, darted out our front door, causing the assembly of first responders to collectively back up. They later shared they quickly determined Cody was curious, not vicious. In her confusion and heavily medicated, Deb fleetingly walked a little way out the front door, initially only focused on getting her Cody-bear back to her. As the first responders started asking her a string of questions, she got flustered and it took a moment for her to collect herself and realize what was happening. She looked around and not only saw all the first responders, but many of our neighbors milling about outside, given all the commotion. All eyes were now staring directly at Deb.

Debbie was devastated. She had on one of her flowery "Moo-Moos," as she scorned them. Understandably, her concerns about how she looked long gave way to her pain and misfortunate. Deb had even stopped wearing her wigs around the house. What hair had started to grow back was now a short, choppy, light brownish gray. But most sorrowfully, Deb still had a surgically precise one-and-a-half-inch stripe right down the center of her head that never grew back. It resembled a reverse Mohawk. Deb had some hair on the sides, yet was bald straight down the middle.

Deb tried to turn quickly to get back through the army surrounding her and back into the house. But she was quite wobbly and unsteady on her feet. A couple of EMTs must have helped her back inside and got her over to her chair, where she unreservedly broke down. Laurie had done her best to explain everything she knew and what was happening with her sister to the first responders.

Some were already familiar. The EMT that looked through Deb's medications, gave her a quick exam, and checked her blood pressure had been to our home several times. Once they could see that Deb was OK and there was nothing more they could do, they collected their gear and filed back out our door.

Whirling Like a Hurricane

With all the house guests gone, Deb gradually regained her composure, especially once she was on the phone with Jeanne. After everyone retired for the evening and Deb, Cody, and I were in bed, I had fallen asleep but was awakened by Deb with an angry voice piercing the silence. Something must have clicked inside her, re-engaging the events of that day as she lay there. Another night of steroid-induced insomnia that her increasing doses of sleeping medication did little to resolve.

"What's wrong, Babe?"

Oh yes, Deb did indeed answer, but using a velocity of language I had not even heard during recent months of cancer- and drug-induced volatility. For lack of a politically correct way of sharing and perhaps more befitting Deb at the time, she absolutely blistered my ass.

Deb was more furious with me than almost at any point in our life together. I had grievously harmed her by my dialing 911. She let me know it with every curse word in the cursing dictionary. While admittedly over the decades I had voluntarily spent a night or two on the couch, this would be a first and a last. As I tried to get a word in edgewise, I lovingly placed my hand on her shoulder, trying to bring reason to the discussion. That lasted two seconds as Deb harshly pushed my hand away.

"Get your fucking hand off me and get the hell out of my bed. I don't want to look at your ass."

Lying on the couch in the front room, staring up at the ceiling, I tried replaying in my head all the words of sage wisdom and solace I had given my sons during these times with their mom. Deb had come at me so hard and so viciously, even with all my logic and reason, I just could not stop myself from being shattered.

Especially as I was deeply distressed at what had befallen Deb that day. During that long, sleepless night on the couch, and to this very day, I second-guess whether I overreacted in calling 911 as Laurie was there, after all. Had I caused Deb such great anguish piled on top of all the other? Having our neighbors see the way she saw herself had ripped at her model soul. Having all those first responders show up at her door, suddenly surrounding and frightening her, sending her into a shock of sorts over it all.

It was a perfect confluence of seemingly disconnected events. Yet they connected in an unimaginable way only Rod Serling could have conjured up in this latest edition of our Twilight Zone. Distraught and sorrowful, I could not fall back asleep. At some point, I heard Cody at the bedroom door. I got up and as I quietly let Cody out of the bedroom, I could hear, blessedly, Deb thankfully fast asleep. I was surprised and warmed that Cody did not want to go outside. But as if to say, "I have your back, man, and I love ya and I'm here for ya," Cody spent the rest of that night laid out by the couch with my hand resting down on him.

I knew the way Deb woke up, that was not going to be one of her good days. I felt horrible for Laurie. Deb was very confused, several times during Laurie's visit even forgetting her sister was in the house. One time, Deb even asked me as she pointed toward Laurie, "Who is that in my kitchen?"

One afternoon I was in my office after the boys got home from school. Laurie came rushing in, crying. She said I needed to go talk with Steven.

"Deb thought she saw Steven breaking some of her angels. Honest to God, he never touched them," Laurie emotionally shared.

"I tried to tell Deb that, but she just started dropping F-bombs, one after the other, at Steven, for nothing. Steven is pretty upset and ran back to his room."

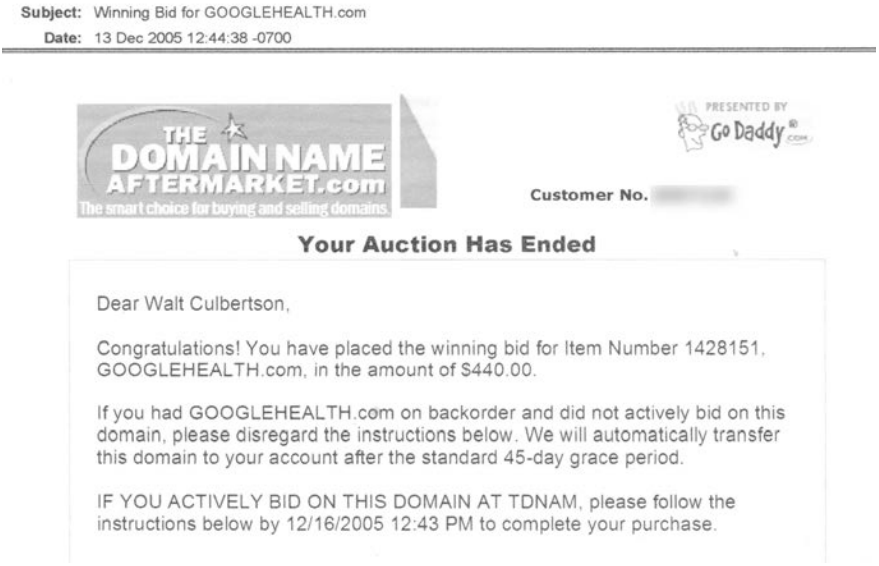
My first task was to try to comfort Laurie. Despairingly, as she had seen walking in our front door, words describing something and seeing that something can be frighteningly different. I knew the way Deb had just gone off on me, even for what the boys had already experienced, this was probably an extreme amplification of their mom's progression.

Steven and I talked, with Thomas joining in, having heard the furor. I always had great sympathy, but even more crushing heartbreak, given my recent Deb encounter of the third kind. She was evolving to be an alien from a different world we did not know. As we sat in Steven's room talking, still greatly hurt, Steven rebounded as always, once again demonstrating true grit, maturity, and fortitude.

One of the bright spots that occurred during Laurie's visit, uplifting Deb, was the afternoon of December 13. For several months Steven, Thomas, and I had been watching a domain sale on GoDaddy for an Internet name and opportunity Deb and I were convinced would change healthcare. "GoogleHealth!"

GoogleHealth.com was coming up for auction. We had placed our initial bid to get us in the game and with hundreds of others sat for months waiting for the big auction moment. My sons had played a few online games against others and following their advice and lead, we timed the end of the auction perfectly and two seconds before the auction ended put in the last and final highest bid. The girls heard the screaming from Steven's room. At precisely 12:44 p.m. on Dec 13 we won GoogleHealth.com for $440.

We rushed into Deb's room and immediately turned what once had been a bad afternoon around as Deb got into the moment. She was excited and cheering on the boys, our boys who had so skillfully helped win the day. For hours, we all sat on Deb's bed, sharing our dreams and plans for changing the world, or at least how healthcare worked within it.



Subject: Winning Bid for GOOGLEHEALTH.com
Date: 13 Dec 2005 12:44:38 -0700

Customer No. [redacted]

Your Auction Has Ended

Dear Walt Culbertson,

Congratulations! You have placed the winning bid for Item Number 1428151, GOOGLEHEALTH.com, in the amount of $440.00.

If you had GOOGLEHEALTH.com on backorder and did not actively bid on this domain, please disregard the instructions below. We will automatically transfer this domain to your account after the standard 45-day grace period.

IF YOU ACTIVELY BID ON THIS DOMAIN AT TDNAM, please follow the instructions below by 12/16/2005 12:43 PM to complete your purchase.

Thanks to some amazing father-and-son collaboration, we won "GoogleHealth.com" so we could change the world of healthcare for their mom!

Perhaps the best way to sum up Laurie's visit is with a collection of her remembrances, reflecting on that last time she would see and hold her sister.

"Of the seven days I was there, Deb knew who I was for four of those days. The other three were very, very bad days. Deb seemed obsessed with Oprah and Judge Judy. I will never forget Deb opening the door and seeing those eight guys on the other side."

More heartbreaking was when Laurie soulfully shared the following:

"I can never forget the way she went at Steven, dropping F-bombs and being so mean when she imagined he was breaking her angels or when she went off on Thomas when she thought he had moved one of her Victorian dolls. It was hard to see Deb with such weight gain and bloating, with such a round face. I wish so much I had come to see Deb in November when she was still kind of OK; December was very bad."

Through the month of December, our wonderful hospice team made at least one house call per week. Some weeks, however, they made multiple visits when I had to call in the cavalry, especially during Deb's bad head pain episodes. Two other gifted and altruistic givers of care, Nurses Donna and Amanda, worked with Nurse Nancy providing in-home visits. Even though we never got to meet them, Nurses Cindy and Becky greatly and skillfully supported us more than one evening in the middle of the night on the Hospice 911 line.

Just after Laurie left, Dr. Neer made more adjustments, increasing Deb's meds. We did see some good improvement in Deb's pain and demeanor for a time. It was fortuitous timing that Deb was able to have a rebound of sorts as we celebrated Thomas's 17th birthday five days before Christmas. Like his brother, his birthday meal was another round of takeout or delivery to go with his favorite cake and ice cream. But once again, there she was. Going through hell and back, yet Deb was beaming once more, standing between her two sons in the candlelight of Thomas's cake. Deb still possessed mesmerizingly alluring blue eyes that still possessed me. Surrounded by a face much rounder, yes, yet still ever so beautifully enchanting.

But that idyllic scene belied the underlying foundation it was built upon. I so vividly recall as if yesterday, staring at Thomas as he bent over to blow out his candles with my heart breaking for both him and his brother. This birthday, like his brother's, should have been a happily prodigious milestone. Instead, this bittersweet birthday commemoration had been set into motion exactly five years before, on Thomas's 12th birthday. An aborted birthday bowling outing that ended with their mom walking out of a clinic with an X-ray in her hand.

A few days before Christmas, my parents arrived for their visit of finality. Understandably yet regrettably, I had seen much less of my family and my mom and dad during Deb's battle than I had my other family and parents Ken and Jeanne. Deb and my dad, Walt Sr., were always close from the day Dad and I met her at the medical conference. But my mom, Rita, and Deb had a deep falling out many years before and were not close. Over the years, they were very cordial, but never as close as Deb was with my dad. While still difficult at times as Deb battled breakthrough pain and a loss of acuity, it would be a warm and peaceful visit with my mom and dad. We were blessed that Christmas of 2005 with Deb feeling a little better.

As our tradition when my dad came into town, he and I left the girls to "cackle," as Dad termed it. On Christmas Eve, we went to our local watering hole. My parents had still visited often enough over the years of Deb's war that Mona the bartender always remembered Dad and was fond of him. Even in a crowded bar, she always gave us special attention.

We got in what little Christmas reverie we could muster, in between my dad wrapping his arms around me. Dad had been through a lot in his life, including war. Nothing rattled Dad. But I saw it in his eyes. Dad was rattled. He was shell-shocked from the bomb that exploded opening our door to see how Deb had transformed and spiraled over the previous year.

"I don't know how the hell you've done it, son."

He told me how soulfully sorry he was for Deb and his grandsons and son, and how difficult it was to see Deb that way, but also his thoughts about the future.

"Like their old man, those boys are pretty damn strong and the one thing I know is what I'm seeing. You three will come out on the other side of this and Deb will be in a better place. This dad couldn't be more proud of you and those boys and Deb for fighting so damn hard."

I received my next wonderful Christmas gift during those hours Dad and I spent together. Back at the ranch, as it were, Deb and my mom had plenty of girl alone time. As both Deb and my mom would later share, they had a good time together. They even had each other laughing. Alone against a ticking clock, they also got into deep discussions at long last. After so many years, they finally "buried the hatchet" that had split them to start with. It was wonderful to see Mom in the kitchen and Deb seated in one of the chairs from the nook, laughing while my little tipsy mom was fussing over Christmas Eve dinner in an unfamiliar kitchen.

We all settled down for our family tradition of watching *National*

Lampoon's Christmas Vacation, starring my exterior illumination hero, Clark Griswold, aka Chevy Chase. The movie was released the year Steven was born and every Christmas Eve since we never missed watching that movie. Every year we laughed and compared notes and even spotted new details we somehow had managed to overlook during the first ninety-nine times we had previously watched it.

After everyone retired, Deb and I took to our other Christmas Eve tradition, wrapping the boys' Christmas gifts in the bedroom watching "our" movie. Every year we alternated boys. Every year it was immediately apparent who the unlucky boy was to have been on the receiving end of Dad's feeble attempts, versus their mom's crisply folded and taped masterpieces, each adorned with perfectly placed bows and ribbons. Mine, not so much. Fortunately, this year the Christmas trend that Deb observed years before continued. The number of items being wrapped got less while the price tag got more!

"Our" annual wrapping movie was our first movie together that magical summer of '83. It was the forerunner to our Christmas entertainment trend, *National Lampoon's Vacation.* Every year Deb and I wrapped and laughed, not just over the movie, but what she did to me in the theater during that movie. In the scene where Clark is speeding down the road with the "unnamed girl in the red Ferrari," Christie Brinkley, I clearly remember saying under my breath:

"That's a nice red Ferrari!"

That is not exactly what Deb heard. To her, it sounded altogether different. In one of her early displays of more colorful language and rare jealousy, Deb turned to me and in a voice loud enough for everybody in the theater to clearly hear, even over the movie, she said, "So you wish you were a damn Ferrari, hah! And here I thought you were a fucking Corvette guy!"

As funny as the movie was, the longest and loudest sustained laughs during the movie were from lines not in the movie. For the rest of our time together, as it would that evening, Christie Brinkley would forever be, "the other blonde!"

Deb was very slowly but carefully staying as focused as she could wrapping each gift, including those special things she so proudly had managed to order by herself off of one of the shopping channels in recent months. I was seated in my chair trying to wrap while distracted, mesmerized watching Deb, marveling over how with such pained hands she was still putting so much effort and focus in each and every crease of each and every package. When the Ferrari scene came on in the movie, Deb looked over and saw that I was staring at her. She dropped her scissors and started to cry.

"If ever there is a damn time you should be looking at that other blonde, it's right now. I'm not that pretty blonde anymore, she's right there," she said, pointing to the screen.

I got up and went over to Deb. She would never accept the truth as anything other than sympathetic appeasement, but she was still so very beautiful. So I did the best I could to bend the focus of that time backward, teasing Deb about what she did to me that day in the theater and all the eyes fixed on me when the lights came on. How I had to slink out of the theater with her strutting out like a peacock. Deb started to laugh. After the laughter came more stories. Before long, the tears were gone and the wrapping recommenced.

The next evening, at the request of Deb and the boys, Dad made his family-famous prime rib for Christmas dinner. He topped it off with what was always a favorite for even my siblings growing up: Dad's baked Alaska. Every time Dad made it for them, Thomas and Steven could never wrap their minds around ice cream going in the oven and still coming out ice cream! It was a great way to conclude Christmas and their visit the next day. Thankfully, Deb had good days and she was genuinely sad to see her in-laws leave.

Platinum Partners

On December 28, our twentieth wedding anniversary, Nurse Nancy made her scheduled visit. She was immediately pleased to see the effects of the last round of medication adjustments Dr. Neer had made. Deb was up and about, walking slowly and albeit a touch wobbly, but nonetheless not trapped in her bed or stuck in her chair. After exchanging Christmas stories during Deb's exam, Deb surprised me. No, make that Deb shocked me.

"You know today is the big one! Today we're married for twenty years. Tonight we're going to go out to dinner and celebrate at my favorite restaurant, Carrabba's!"

This was totally news to me. We had already planned I was making Deb one of her favorites, baked barbecue chicken in the oven with my special sauce. Before I could get a word out, Nurse Nancy did.

"Why that's wonderful, Deb, what a nice way to celebrate!"

Now looking over at me, she added, "You should be fine to get out for dinner, as long as you use the wheelchair."

After Nurse Nancy left, Deb did indeed confirm our change of plans, much to the delight of the pizza-brothers. That evening Deb picked out the least loud "big-ass Moo-Moo," as she now labeled them. She next took my hand and slowly walked me over to the closet. She positioned herself in front of her wig rack and pointed.

"What girl do you want to be with tonight?"

Deb had a row of top-of-the-line wigs in different lengths and colors she had ordered. They were in various shades of blonde to red. My favorite was always the one that most resembled the way she used to keep her hair just before she got sick. When I pointed to it, Deb said with a smirk, "Oh, you want to be with that old boring girl again."

I hugged her as tightly as her broken body would allow.

"You better believe it!"

When she was ready, Deb slowly started to make her way to the door with her purse under her arm. I knew my next task would be the most difficult of the evening.

"Babe, please at least give me a chance to get the wheelchair out and into the tribe-mobile."

Without stopping or looking back at me and a touch uneasy on her feet, Deb wobbled her way to the front door, opened it, and walked out, talking over her shoulder.

"I ain't riding in no damn wheelchair and I ain't getting in no damn Pacifica. The only time we ride in that thing is when we're going to the doctor or the hospital and that's not where we are going."

I caught up to her standing by the driver's door of the Corvette, waiting for me to open her door. Of the three Vettes we had together, the blue ’79 when we met, the red ’72 coupe I traded in for our first tribe-mobile, and the ’96 Collector Edition she dubbed the “silver bullet,” that ’96 was her favorite. Before she got sick, anytime she and I went anywhere without our sons it was always in a Vette. Even during her year-long clinical trial with the miracle cancer pill, Deb looked forward to those five-hour round-trip “silver-bullet” journeys.

But on this night, no matter how long or short the journey, Deb could never make this one in that Vette.

“Come on, Babe, we need to take the wheelchair as Nurse Nancy instructed. Even if we could get you in the Vette, there is just no damn way you would ever get out of it. You just don’t have the leg strength, Baby. We just can’t do it!”

Deb and I went back and forth and she started to become louder, her Dutch determination now in a dander. But the longer she stood, the more she started to lose what leg strength she did have. I went over and rested her against the door of the Vette and rested my hand on her cheek, staring into her baby blues.

“Look, Babe, you see how weak you are, there’s no way I’m going to get you in and out of this Vette. We have to take the Pacifica.”

She got a tear in her eye and quickly wiped it away.

“OK. OK, I’ll ride in that damn Pacifica, but I ain’t riding in no wheelchair or walkin’ with no damn walker. With your help, I’ll be able to make it there and back OK.”

With no more discussion, nor the chance for it, Deb pushed her rear end up off the Vette. She started guiding me as I supported her toward our tribe-mobile. It was still a struggle to get her up and into her seat. I closed the door, in Deb vernacular, scared shitless. On one hand, I certainly understood why there was no way Superwoman, this proud, South Side, tough-as-nails Chicago girl would ever ride into that restaurant on our twentieth wedding anniversary in a wheelchair. But on the other hand, I just could not imagine how she or I were going to ever pull this off with her so weak. I was now the one cussing, at myself for not having loaded the wheelchair earlier.

Fortunately, as typical for restaurants in between Christmas and New Year’s, Carrabba’s was not overly crowded. As I recall we were able to get a handicap space right up front near the front door with no handicap parking debate from Deb. Superwoman often refused to use that space. I can still feel Deb tightly gripping my arm. So much so, the next day I had bruises. We slowly progressed from the parking lot up to the hostess who was, fortunately, able to quickly seat us in the middle of the dining room. Thankfully, Deb followed my suggestion that it would be far easier to get her up and down out of a chair versus in and out of our normal booth seated side by side as we typically did.

The candle was already lit on the table and overhead lights dimmed. I am certain Deb must've ordered her normal steak Marsala, but I don't remember even looking at the menu. On this our twentieth, as I had been attempting for the past year-plus, my gaze and focus were on burning every image and every detail of the beautiful blonde who came strolling across that conference room floor toward me twenty-three years before.

Even as Deb knew her journey was withering ever shorter with each passing day, she courageously confronted this harshest of human realities. I remain overcome by her courage, tenacity, and perseverance. Fueled by her powerful meds and so much to share against the backdrop of a ticking clock, Deb drifted in many directions.

At times, she brought herself to tears, especially as she talked about not having had enough time with her three boys. That she would never see her grandchildren. Why was she reliving this torturous reincarnation of her painful childhood? All these years later, it was she trapped with the same disease and the same progression. Just like her mom and dad, she and I had to fight both her illness and a healthcare roulette system that had seemingly changed little through all those decades. Only this time it was her sons and those she loved living in her harrowing childhood nightmare.

Etched forever is the image of Deb's porcelain face stained with tears glistening through the candlelight. Throughout the evening, before her tears could linger or accumulate, Deb stoically wiped each away and continued forward. Deb sprang about randomly among the special things she wanted to make certain she shared on this of all special evenings.

Among them were as well her thoughts about my future. Perhaps uncharacteristically a heartwarming Rod Serling script, but another episode of *The Twilight Zone* nonetheless. I spent some of my twentieth-anniversary dinner with the woman I married twenty years before, who spent the last year mad as hell at me for not divorcing her over medical bills, now explaining to me in gory detail her planning for my next wedding.

“I know no one is ever going to replace me for the boys and my Cody-bear, and I know it’s going to be hard for you to go on after I’m gone. But I don’t want to see you moping around alone, and I don’t want to see our boys without a mom.”

Deb’s gaze drifted down to the table. “So what I’m thinking is that a year is enough of you moping around about my ass. In two years, you’re going to be remarried to a nice lady who cares about our boys.” Deb put her hand on mine staring intently into my eyes.

“You ain’t going to be marrying no blonde floozy or someone twenty years younger than your ass, either. You already know who would be good for you and the boys, and I want you to think about her.”

At this time of all times, Deb was not thinking of herself, but desiring to know those she loved were going to move forward after she was gone. I would find out in the months to come, Deb had this discussion with many, from her mom, sisters, and aunts, to my mom and dear sister Cathy, who was always close to Deb, and even my Uncle Cal and Aunt Charlotte in Baltimore. Deb told each fully her game plan and that she expected two years after she was gone, I would be remarried and they needed to help push me in that direction.

At some point, I believe after we ordered the chocolate dream dessert Deb always loved, she was all about chocolate, after all, I surprised her. I put my cell phone on the table and played our song. You could barely hear the Eagles “Peaceful Easy Feeling” through the noise of table discussions surrounding us. But it was a heartful mistake as we both stopped talking and listened with watery eyes. We struggled to wipe away our tears as we shared those private things and our thankfulness through thick and thin, through all those years of ups and downs, we were still seated at the table together.

I remember looking at Deb knowing we had outstayed our welcome. She had pushed back her pain and pushed back the wheelchair and was pushing herself to the edge. As I attempted to help her from her chair, my feared observations became realized. Deb had little leg strength and even with all I could muster, I just was not getting Deb up and standing. To the loud screeching of a weighted chair moving across the floor of a now-crowded dining room, I attempted to angle Deb slightly to better get underneath her. I tried several more times but simply could not help her get to her feet.

I looked helplessly about for our waitress. I had a glimpse into how Deb felt when she walked out and saw all the neighbors. Only now, it was I, as those in the dining room stared with their eyes fixed on us. An alarmed waitress from an adjoining area and I made eye contact. She quickly reacted to the S.O.S. I was sending with my eyes. She immediately stopped what she was doing and came rushing over and to our rescue. She softly spoke to a now-very-flustered Deb for a minute as I thanked her. She looked at us both and confidently declared, "We're going to get you up and on your way, dear, and everything will be fine. When you're ready, we'll get you up!"

The angel of a waitress calmly mouthed, "One-two-and-three," and with that, we got Deb up. Her wig had shifted during the tussle and was now a little crooked on Deb's head.

"Let's get your beautiful hair lookin' the way it should," she warmly said to Deb as she helped straighten her wig.

As she positioned Deb's hair perfectly, Deb straightened herself up. With the waitress under one arm and me under her other, Deb lifted her head high and proceeded as if she owned the place. We slowly made our way out of the dining room and toward the door. Two other servers popped open the two sets of front doors while the waitress continued by Deb's side all the way to our SUV. She helped me get Deb into the front seat and gave her a warm hug and then turned to me. I continued to profusely thank the waitress as we hugged. The waitress started to walk away but turned around, came back, and met me at my front bumper.

"Please wait here for a minute. I have something I need to give your wife. I'll be right back, I promise."

A few minutes later, the waitress rushed back past me to Deb's door. She bent down and they had a quick conversation and they again hugged. She then turned and came over to me.

"God will bless and keep your beautiful wife and you and your family."

She hugged me once more before disappearing through the restaurant front doors, certainly aware of the several tables of customers wondering what had happened to their waitress.

Deb was again in tears, only these were joyful tears. She proudly showed me a smoked brown glass pendant with a beautiful ivory angel inside. The waitress told Deb that someone had given that to her during a time of great loss for her and she wanted Deb to have it and keep it with her always. The waitress called it her guardian angel, her prayer stone.

I remain so deeply touched by the great caring, heart, and kindness of that waitress. Such a generous act and sacrifice, to have given something so cherished to someone she did not know and had just met. Later that evening back home with Deb, I felt great sorrow, yet great hopefulness at what was beyond. Renewed once more in not just that which we can't see, but that which we can and that which touches us, our fellow man.

The "Prayer Stone" given to Deb by the most caring and herself angelic waitress. She came to our rescue the evening of December 28, 2005. I shall never forget her!

Deb would come to keep the prayer stone rarely out of reach. So many times over the weeks to come, I would retrieve it after she dropped it losing her grip or dozing off, always pressing it back into her hand as Deb was almost panicked to be without it. It is now I who cherishes this stone. I gaze at it often and reflect on that twentieth-wedding anniversary dinner. I wonder whatever happened to that most special person who caringly came to the rescue of two strangers in the middle of a crowded dining room. She so selflessly bestowed the greatest gifts of all. Help, hope, and love.

We spent the previous New Year's Eve with Deb soundly asleep, about to begin her battle anew. I had heart-wrenchingly lain in bed next to her, rubbing Cody's head, sipping on Crown, lost in contemplation about this journey ahead. A year that felt more a lifetime later, Deb was now not sleeping. With a strong dose of steroids in her system and her sleeping pills ever less effective, Deb was wide awake. Not long before midnight, she decided she wanted to change into one of the silk pajama sets I had gotten her for Christmas. She picked out the pink one.

Over the past months, I found the easiest way to help accomplish getting Deb changed was to use the side of the bed. As Deb sat up on the edge, I first helped her get her dress, or in this case pajama top, over her head. I then got the bottoms up as far as I could with Deb seated. For the final step in our maneuver, I helped Deb stand to her feet and lifted the pajama bottoms into place. Her new pajamas did look fashionably wonderful on her. Deb sat on the bedside for a moment catching her breath and looking down and admiring her outfit.

Without warning, Deb suddenly and harshly coughed and tried to catch her breath. Then, in a series of short, fast coughs, she started coughing up blood onto her new pajama top. She coughed a few more times as I was reaching for the tissues on her nightstand. Even with my Navy medical training, I must have been a deer in the headlights when Deb looked at me. She calmly took some of the tissues from my hand and helped me wipe the blood from around her mouth and dabbed at the blood on her new pajama top. I grabbed more tissues and continued helping, I'm certain my hands shaking as I did so.

Deb handed me her tissues and placed her hands on each side of my face, pulling me toward her, staring calmly and serenely in my eyes.

"It's OK, Babe. Everything's OK, I'm fine now. It's just a little blood. Just sit down here next to me for a minute."

Admittedly, I was too terrified to do anything but comply. But my next thoughts were to immediately jump on the phone.

"I'm going to call hospice and get somebody here immediately." But Deb stopped me in my tracks.

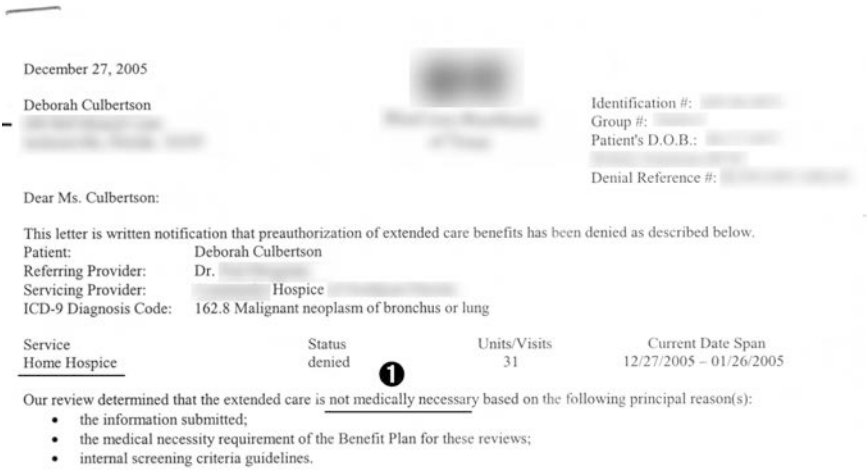
"I'm OK now and we don't need them out here in the middle of the night. It's just a little blood. I'll be fine if you just help me get this top off and soak it in the sink in cold water and get me another top."

After a torturously long, sleepless night spent in my chair watching over Deb, I called Hospice 911 early the next morning before Deb could even stir. Mere hours later, our Nightingale Nurse Nancy was thoroughly examining Deb. After they said their goodbyes, Nurse Nancy and I walked out and sat in our front room. She shared with me what she purposefully and justifiably did not wish to share with Deb. This was the progression and way of things. Sadly, we were likely to see more. Nurse Nancy's advice concluded with instructions to always keep a dark or red towel near Deb's bedside. It would help mask the situation if needed when the time was right.

Several years prior, I had gotten a copy of Dr. Sherwin Nuland's *How We Die* prior to going to New Orleans the first time we thought we were going to lose Deb. But I never could bring myself to read it until after Deb entered hospice care. I had burned much midnight oil on the Internet reading everything I could to prepare. But hearing those things I had only read about, and hearing them from Nurse Nancy with her hand upon my shoulder, made it altogether painfully real.

Nurse Nancy was concerned enough about Deb's condition that she sent Nurse Rose out the next afternoon to examine Deb again. I vividly relive that afternoon of such consequence, not for Deb as I never told her, but for me. As Nurse Rose arrived, I was in my office silently screaming at the top of my lungs, looking at the notice that had been among the first in our box to herald in my New Year. It was from our insurance company!

Our health plan denied Deb's hospice care renewal for another thirty days. It was adjudicated as "NOT MEDICALLY NECESSARY" by those who make "the real" healthcare decisions in America. It's not our doctors; it is lavishly paid bureaucrats and administrators flying about on corporate jets paid for with our insurance premiums. Without any word of warning before that notice, Deb's hospice coverage had actually been terminated a week earlier, the day after Christmas.



December 27, 2005

[redacted]

[redacted]

Deborah Culbertson
[redacted]

Identification #: [redacted]
Group #: [redacted]
Patient's D.O.B.: [redacted]
[redacted]
Denial Reference #: [redacted]

Dear Ms. Culbertson:

This letter is written notification that preauthorization of extended care benefits has been denied as described below.

Patient:	Deborah Culbertson
Referring Provider:	Dr. [redacted]
Servicing Provider:	[redacted] Hospice [redacted]
ICD-9 Diagnosis Code:	162.8 Malignant neoplasm of bronchus or lung

Service	Status	Units/Visits	Current Date Span
Home Hospice	denied	31	12/27/2005 – 01/26/2005

❶

Our review determined that the extended care is not medically necessary based on the following principal reason(s):

- the information submitted;
- the medical necessity requirement of the Benefit Plan for these reviews;
- internal screening criteria guidelines.

***Learning Opportunity**: ❶ At the end of the day, or in this case your life, it is not your doctor who controls your passage. It is your insurance company.*

The first week of January 2006, Deb wasn't the only one who ended up being examined that afternoon. I was Deb's first mate on this most unlikely of difficult journeys after all. I was equally exhausted from navigating so many difficult curves along the way, one atop another, replete with dueling sleepless nights and restless days. But now, with so much rage flowing through me, instead of the steroids flowing through my shipmate. I keep reading that notice over and over again. My hands shook uncontrollably just holding it.

After Nurse Rose's exam of an in-and-out sleepy Deb, we sat in the front room and I am not certain the trigger. But she started peppering me with questions. I don't recall what I said and can only imagine how I looked, but she ended up checking my blood pressure. It was very high. Nurse Rose wrote me a clear verbal prescription.

"You can't take care of your wife and those boys if you're not taking care of you. You need to immediately get to your GP and get that BP looked at."

I knew she was sadly correct on all counts. Fortunately, the timing was finally in my favor. Jeanne was coming for another visit and I would have cover for Deb while I was gone. I very much adore my primary care doc, but over the years, it had become increasingly more difficult to get appointments. When I did get in, most often, I only got to see one of the PAs. While all are extremely caring and competent, they are still not the doctor I signed up for or who my hard-earned insurance premium dollars were paying for.

But still, all those from my doctor to her nurses and staff were always most courteous and kind. While getting appointments typically took four weeks plus unless an emergency, the scheduler caringly listened to my sob story and diligently worked me in for one afternoon that week.

I was truthful with Mom and Deb. I was going to get out of the house for a bit, run some long-overdue errands. I would conclude my outing on my way back home with a long overdue visit to our local grocery store with an equally long overdue grocery list. I just sorta neglected to share the part with them about my blood pressure screaming and the appointment with my doctor.

To my surprise, despite my mental complaints, it was my doctor, Dr. Vicky, who walked in the exam room. She can be stern, especially when you're not following her advice. But she's a physician who deeply cares about her patients. It had been a while since we had seen each other. I had been seeing others in her office over the past few years for my checkups and to renew a preventative med for my once-upon-a-time cluster headaches. Her team had already worked up my basics including blood pressure and ran an EKG. With my records in hand, my doctor walked in the exam room as that old saying, loaded for bear.

"Well Walt, you look like shit. What the hell is going on?"

After giving her the CliffsNotes version, she thoroughly examined me and sat back down next to me.

"If you keep going like you're going, Walt, those boys of yours are going to lose a whole lot more than their mom. You have to figure out a way to start de-stressing in any way you can. You need to start drinking more fluids, you're dehydrated, and you've lost a lot of weight since last year. You have to start eating better and trying to figure out some way even in between all you have going on the home front to get more rest.

"I'm surprised your erratic sleep schedule, your stress level impacting your blood pressure level, hasn't triggered episodes of the last thing you need right now, a return of those cluster headaches you once had. I am going to up your Verapamil dose and put you on a blood pressure med I want you to start taking at bedtime. If anything else changes, get in immediately. Otherwise I want you back here looking better in four weeks."

She hugged me goodbye and shared her final verbal summary-of-care report.

"I'm so deeply sorry to hear everything going on with your wife, but I want you to start better taking care of yourself, Walt, for you and your family."

It seems like only yesterday I sat in Deb's silver-bullet in the small parking lot of my doctor's office under the shade of a tree, staring at that script. My doctor's intention was to place words upon it symbolizing the medication I needed to help lower my blood pressure. But at that moment, the script was having the exact opposite effect.

Over all my years of self-employment, we never went without insurance, but I struggled mightily and paid dearly to obtain a policy just because of a long-dormant label, "cluster headaches." But from all my years working with insurance companies, I devastatingly held that script knowing this second diagnosis was an insurance death sentence. It meant that I would now be forever further labeled and scorned as a "sick American." My doctor might as well have written on her script, "Rx—Screwed!"

A few months later, when I finally attempted to get a new policy, that was precisely what happened. I was up-charged "seventy-five percent" for having received that prescription, on top of trying to pay for that prescription. At over $100 a month out of pocket with insurance, it was obviously still not cheap. These are part of the consequences of being labeled a "sick American!" This ultimate label, labels more Americans than not.

[redacted]

April 28, 2006

Walter L. Culbertson, Jr.
[redacted]

Agency: [redacted]
Product: [redacted]
SSN: [redacted]

Dear Mr. Culbertson:

Thank you for your application for health insurance with our company. We are pleased to advise that your application has been approved and coverage begins effective April 1, 2006.

Your application and medical information have been reviewed and your contract has been issued with a Rate Modification. A copy of the Rate Modification is enclosed. A rate modification of 75% was imposed due to your history of high blood pressure and cluster headaches. ❶

Due to the rate modification, an additional billing notice will be sent to you separately. In order to accept this coverage, please remit this additional premium payment. Once this is received, your coverage will be placed on a current billing date. If you have any questions, please contact your sales representative.

We look forward to being of service to you.

Sincerely,

Individual Medical Underwriting Department/
Enrollment Department

***Learning Opportunity**: ❶ The plight of small self-employed Americans and others purchasing individual insurance. While so-called "guaranteed issued policies" "guarantee" the insurance company must write the policy if you had no break in coverage longer than sixty-three days. They do not have to "guarantee" you will be able to afford the policy. You can still be penalized. In this case a 75% upcharge.*

My dad Ken came into town over the weekend to join Mom. Sadly, before any of us could blink, that time came and went. Over those days, Deb's pain and mental impairment had accelerated. Monday morning, Nurse Nancy made her planned weekly visit. After examining Deb, she increased her meds, including for pain. Nurse Nancy left after caringly giving us her thoughts and hugs all around. With that frank assessment, it was with great trepidation that Mom and Dad left later that afternoon. Every time I watched them back out of the driveway, it had become increasingly more heartbreakingly difficult, this time with more foreboding. My sons, Cody, and I were left alone with hospice to navigate this treacherous stretch of our journey.

Just hours later, into the night and early morning of January 10 at 2:30 a.m., Deb awoke unable to breathe. Of all feelings, this understandably was the one most starkly terrifying for Deb. In the past, this only occurred when one of her lungs collapsed. But Deb did not quite exhibit all the same symptoms. She was not experiencing sharp, stabbing pain in her chest as before. But Deb was having a hard time catching her breath. I sprang up, startling Cody, and finally had to put the oxygen we had been renting for almost a year to good use. I quickly decided right or wrong to start with the nasal cannula rather than using the full mask to keep from scaring Deb even more. Using my stethoscope, I could hear air going in and out of both of her lungs. I checked her blood pressure, which was high but not extreme; however, her pulse was definitely racing.

In a reverse of our New Year's Eve incident, it was now Deb with the deer-in-the-headlights look as I took charge. I coached Deb to breathe in and out more deeply, and with every breath, she was able to do so more easily. While her breathing was still somewhat labored, after a few minutes she was breathing better and far less panicked. I called hospice 911, and based on my report, the nurse concluded there was not much else they could do other than what I already had. But they would leave a message for the morning nursing corps. I received an early morning call from Nurse Nancy that she was on her way and by 9:30 a.m., she was at Deb's bedside examining her. Deb was doing OK, but she would arrange to get more oxygen in the house and for me to keep Deb on it at all times going forward.

The Long and Winding Road

From then on, I continually fought Deb over her pulling the cannula out, especially while she was sleeping. We tried the oxygen full-mask but Deb just did not like wearing it. I had to sit guard, putting it back on her throughout the night as she would uncontrollably pull it down in her half-sleep. It had quickly become much more difficult to get Deb in and out of the bedroom and back and forth to her front-room chair. It was impossible to get the wheelchair past our old nemesis, the alcove in front of our bedroom door. Deb got insistent on staying night and day in the front room in her recliner.

As much as she loved her fancy bed, it had become a prison. Deb loved her recliner and the spot it sat in, able to look all about the house. Deb could watch her Cody-bear and the other entire goings-on in the backyard to her left. Straight ahead, she had her big-screen TV, where she could glowingly watch *Oprah*. Just to the center right, she could wave at Puffy the "blue-eyed-slut" over in her cherished aquarium. To her right, Deb could watch all the activity in the kitchen and the boys come and go.

During her second night in the chair, I was on the couch clicking away on "Mary" when Deb awoke in the middle of the night. She was talking loudly and repeated the same thing over and over.

"I smell baaacon. I smell baaacon. I smell baaacon."

I could not stop myself from busting out laughing.

"Well, Baby, there is no bacon cooking anywhere."

Deb drew the first genuine smile I had seen on her face in a while. "Yeah, now that's the damn problem, ain't it. 'Cause I ain't smelling no bacon either, and you can't take a damn hint. I want to start losing some of this weight, and I heard on *Oprah* if I ate bacon, I'll lose weight."

As if Deb had totally forgotten about our last "Oprah bacon" adventure, she again presented with great seriousness her "Oprah theory of bacon," then took aim at her Cody-bear.

"Looking at biscuit butt's ass layin' there, you better make him a shitload while you're at it."

Two words Cody loved to hear in the same sentence, his name, and food. He heard with his German shepherd ears Deb say the "b" word, as the boys and I resorted to calling it. Before I could put my laptop down and get into the kitchen, Cody had made a beeline and had his biscuit-butt parked in front of his biscuit jar. Deb started laughing. I could not believe my ears as great warmth filled my heart. Deb was laughing and teasing Cody about getting a biscuit. The more he danced, the more she teased him and the more she laughed.

The entire time I was frying bacon and getting our eggs ready, which I hoped to get more down Deb than the bacon, she magically transformed into a chatterbox. While obviously heavily medicated, she nonetheless was stringing whole sentences together. I had my Deb back. There she was. I don't know who that other person was for all those weeks. But there was Deb.

I sat down in the middle of the night, eating eggs, Oprah bacon, and toast once more with "the Deb!" Yes, as you might surmise, her moose Cody not only got his bacon but most of Deb's. For the record, Cody, like Deb, never lost any weight eating "Oprah bacon!" Over the years, I'm certain some may have witnessed me sitting at an otherwise quiet breakfast table, with no other reason than the smell of bacon, to be wearing such an intractable grin.

As Deb was now staying night and day in her chair, I ended up keeping the porta-potty chair handy and used a large sheet to hold up around Deb for privacy. On the morning of the 12th, Deb awoke to her third night in the chair and waited for the boys to go to school to use the potty. It was difficult enough just to help lift her up from the recliner. But the next step of the procedure was holding her up while positioning her precisely in front of her potty and lifting her muumuu high enough to be out of the way. Then I simultaneously pulled down her underwear with my final step of helping her sit down. Deb had weaker leg strength with each passing day, and this time as Deb sat, the potty chair almost toppled over, taking Deb with it. It took every ounce of strength I never knew I had to keep Deb and her potty upright.

After she was done came the final step of getting Deb back in her chair by reversing our difficult procedure. I got as far as Deb up from the potty and her underwear pulled back up, but as I turned her to position her in front of her recliner, Deb suddenly lost all leg strength. She was dead weight in my arms and was going down fast. All I could do was put her down right where we were, just in front of her recliner. With her back now resting against the recliner, we sat for a while and recovered.

I made my first attempt at getting her off the floor and into her chair. More than half a dozen tries later, Deb was still on the floor. I started telling Deb that I had no choice but to call someone. There was no way I was going to be able to get her off the floor by myself.

Deb begged and pleaded with me not to call anyone. She wanted no one to see her that way. But after several more attempts, Deb finally agreed to let me call Mr. Bill. His phone went straight to voicemail and I left a message. She let me next call Nurse Nancy, who was out making rounds and I left a message. Another hour went by and we were still on the floor. We kept trying to get Deb up until we were both physically exhausted. She just had absolutely no leg strength. Complicating things greatly, she was not the slim, trim Deb anymore.

Now well over two hours on the floor, I told Deb I had no choice but to get the EMTs there. Again, Deb begged me not to. I got over next to her, eyeball to eyeball, and we stared intently into each other's eyes.

"Baby, we are going to try this one more time, and if we can't get you off this floor, I'm calling 911."

She nodded her head, disgustedly looking down at the floor, not wanting to make eye contact. I got into position.

"OK, Baby, I'm going to pull up with everything I have in me, and you're going to push up with everything you have in you! One-two-three!"

I could feel Deb still had little leg strength, but I continued pulling upward. I don't know how the hell I did it. Perhaps this was not quite the scene in the movie or in the news where a person single-handedly lifts the car off someone. But bending over and getting Deb off the floor with the weight she was then carrying, after so many failed attempts, seemed in the moment Herculean nonetheless.

But I quickly realized I was no Hercules or superhero like Deb. I remember getting Deb completely back in her chair and making certain she was OK. I think it was when as I straightened up, I felt tremendous pain, almost an electric shock, come across my back in the center of my chest, doubling me over. It felt as if I had been punched, but it quickly subsided. Without saying anything to Deb, I sat on the couch just to the left of Deb's chair in front of the wall of windows.

I sat for minutes, paralyzed, wondering if I was having a heart attack as I looked over at Deb starting to close her eyes. She was clearly worn out from the hours of floor tussle and struggle. I remember thinking of all times, I can't call 911 again, this time for me. I lay down feeling myself start to go out. I so starkly recall my last direful thoughts.

"God, please let me wake up."

I very obviously did. Many hours later, now late afternoon, our sons were home from school and Thomas was standing over me waking me up. My cell phone was ringing. It was Nurse Nancy, who had also tried to call several times earlier on the house line, along with Mr. Bill. Foggy from both exhaustion and the events of earlier, I explained to her that Deb had lost leg strength and I had a difficult time getting her back in her chair. Nurse Nancy knew Deb treasured being in the front room but suggested what I already knew. At this point, the best place for Deb was back in her adjustable bed and using a bedpan. Nurse Nancy would plan another visit first thing the next morning.

I felt no lingering aftereffects from the morning and trapped in the middle of a hurricane, I said nothing to anyone about what happened to me. After that discussion with Nancy, I gathered my wits about me, and proceeded on to my next task at hand, hustling together dinner for the family. During this time, Deb's food intake became less and less. She was most probably sleeping as the boys and I had dinner and I shared our forthcoming "Movin' Mom Maneuver!"

I had assessed that while we could not get the wheelchair through our menacing bedroom door, we would at least use it to get Deb from her recliner over to the alcove in front of the bedroom door. Then with one boy behind their mom and the other with me in the front, we would work together to get their mom up out of the wheelchair and through the bedroom door. The other boy would move the wheelchair out of their way enough to come through the door, and all three of us would then maneuver their mom over to her side of the bed and into it. Once Deb was awake and talking, I shared the discussion I had with Nurse Nancy and summed up our game plan.

"Once you're ready, Babe, the boys and I are going to get you back in your bed so you can get some sleep tonight!"

The battle I expected to receive did not occur. After several nights sleeping in her chair, and the hours struggling to get her off the floor, Deb quickly surrendered and was ready for her fancy bed. The “dude” plan worked flawlessly. Deb was in her bed but she had another very difficult night. Her pain was starting to intensify, not as much in her head now, but in her bones and joints. I was starting to wonder if her cancer had metastasized to her muscular-skeletal system.

It was another long, restless night, and I rose out of bed on the morning of Friday the 13th more exhausted than when I went to bed the night before. I was in the kitchen most probably futzing with coffee at precisely 8:30 a.m. when I looked at the stove clock.

I heard Cody loudly yelp, and Deb screaming, “Walt!”

Cody immediately came out of the bedroom anxiously limping in circles, watching me rushing over as he darted back into the bedroom. When I got to the bedroom door, I did not see Deb in bed but Cody hovering around Deb’s side of the bed. I found Deb lying flat on her back on the floor.

Evidently, Deb had woken up and was determined she would not spend her day trapped in that bed. I got down on the floor and sat her up, looking at her head and trying to make certain she was OK. I put her oxygen back on her and dragged her a little way over to my chair, resting her back against it. I continued my exam. Deb had a long scrape on her left forearm, but her right ankle was already starting to swell.

Knowing Nurse Nancy would hopefully be there soon, I debated what to do next. Deb continually told me she didn’t want me calling anyone and certainly not the EMTs. She wasn’t going anywhere no matter what she broke. She was more concerned about her Cody-bear. As typical when she was getting out of bed, Cody must have been standing next to her bedside when Deb went down. She most probably landed partially on Cody, who was nursing his right paw. Fortunately, I felt nothing broken and saw nothing serious. Unsurprisingly, Cody had truly been there for Deb. He helped break her fall.

I once again found myself on the floor with Deb, this time holding ice on her forearm and ankle and staring down the time on the cable box. I think it was around 10:00 a.m. when the doorbell rang. Nurse Nancy quickly made her way to the bedroom and did a quick visual exam with Deb still on the floor. I pointed out Deb’s ankle and Nurse Nancy distressingly looked inconsolably up at me after examining it closer. Deb was still rattled and in a lot of pain, but otherwise OK. We knew she would never be able to put any weight on her legs, so we got Deb as close to her bedside as we could. Again, there would be the all-important countdown.

"One-two-three!"

We got Deb up and back in bed and Nurse Nancy examined Deb more thoroughly and gave her a shot of non-morphine pain med. After a few minutes, Deb started to relax as her pain eased. She sat by Deb's bedside for the longest while until Deb was falling in and out of sleep. We walked to the front room and she told me Deb's ankle very well may be broken, but there was really nothing we could do except keep Deb out of pain and keep her in bed. Nurse Nancy suggested going forward it would be too difficult to use a bedpan. It would be best to put a catheter in Deb. She needed to check in with another patient in the area, and then would swing by the office and get the needed medical supplies and come back.

For the rest of the day, I sat in my chair next to Deb's bedside, watching her sleep, bewilderingly studying Deb lying in that bed and heartbreakingly knowing she would never be out of it again. Feeling as if I had been stuck with a giant pen and everything from within was coming out in a rush of air. Many times in our life, Deb literally took my breath away. Now in a way I could have never foreseen nor wanted to. All the air was being sucked out of me, leaving a collapsing, crushing void behind.

When Nurse Nancy arrived, I asked Deb if she wanted me to remain in the room. She reached up for my hand, pulling me down as I sat on her bedside. Nurse Nancy donned a set of gloves and got Deb ready. Deb and I locked eyes. Over the minutes, Deb's blue eyes ever so slowly turned a reddish hue and started to water. For her sake and perhaps mine, I was stoically determined not to do the same.

After many minutes, I looked down and Nurse Nancy was still struggling to position her light and keep Deb's legs in the right position and insert the catheter. I volunteered to help. Nurse Nancy accepted. Working together while I kept the field open and held the light in place, after a couple more attempts Nurse Nancy accomplished what she needed to. As I assisted with the procedure, I had tried to keep my focus on what Nurse Nancy was doing. But I instead could not stop myself from looking up at Deb as we again locked eyes. I will forever see and feel the solemn hauntedness in her blue, red-stained eyes.

Given Deb's ankle and already elevated bone pain, Nurse Nancy placed a call in to Dr. Neer. Deb was increasingly more nauseous, so we also needed to try to switch her to as many liquid medications, patches, or suppositories as we could. Before leaving us, Nurse Nancy gave Deb another pain shot before she left, hoping that would help the rest of the evening and into the night. It did, for both Deb and me.

Over the following days, Deb kept lapsing in and out of lucidness. She developed a pure hatred for the oxygen tube and kept trying to remove it. This became a constant battle. Sometimes Deb was very aware and knew what was happening around her. During those times, Deb was most often inconsolable and miserable, trapped in her bed. Her room was spinning once more and Deb was in more pain than at any point in her battle. Other times she would mumble and talk to herself, pointing to the walls, TV, or Cody. Whether she was lucid or not, Deb wanted Cody by her side. He was her safety blanket, even calling out for "him" when she could not remember Cody's name. He never left her side.

Exactly one week later, Deb had another terrible Friday. She was in great pain all day going into the night. The pain seemed to be coming from everywhere. Her head, her chest, and her HOA was raging. Additionally, I can only deduce based on the way she described it, intense bone pain. She spent another day and night nauseous, unable to keep anything down. It was well into the night and I was once again trying to get the liquid pain meds down her and she coughed it up all over herself.

Deb weakly reached up, grabbed my shirt with both hands, and pulled me down, almost making me lose my balance and fall on top of her.

"Please, Baby. Please just end this now. Please do whatever you have to, just stop all of this now. Please! I beg you. Please take away my pain and all this now."

For the next several hours as I held her, she begged me to end her life. I devastatingly continually tried to get the liquid down her. More was coming up than staying down. But eventually, I got enough to have an effect. Over the hours, she slowly stopped begging me to take her life and slowly lapsed back into sleep. I was left sitting in my chair by her bedside, exhausted. After hours of my wife begging me to kill her, I lay back in bed holding her. I was deflated, despondent, and heartbroken.

But Saturday morning, hospice delivery was at the door once again, dropping off the next batch of medications. Deb was now pretty much on the maximum doses of everything. The latest anti-nausea suppository must've helped somewhat. Over the weekend, Deb was not as nauseous and I even got some food in her. While not everything stayed down, enough of it did that she had a far better weekend than the week before.

As in our front room, we had tall, wide windows overlooking the backyard. So many emotions flooded me after the week we had, to see Deb's bed upright and her gaze focused on the window, smiling widely watching Steven and Cody chase each other around in the backyard. They were putting on quite a show for Mom.

Whenever Deb wanted the blinds open and light streaming in, I knew those would be good hours. But when she wanted them closed and the room dark, those hours were as her room, very dim. When Deb went into hospice care, I had tried to do all I could to prepare for this ultimate eventuality. I received warm and sage wisdom from Aunt Shirl and Mom. They were both lifeline and godsend. I spent much time reading and rereading Dr. Sherwin Nuland's *How We Die.* Everything the good doctor shared I benefited from, including recognizing the signs emanating from a dim room.

The beginning of the week of January 23, 2006, Deb slowly slid into more periods of a semi-lucid-sleep kind of state, at times talking to herself. She was not fully waking up for longer stretches at a time.

Deb had many times commanded me when her time was near, she did not want anyone but our boys, her Cody-bear, and me with her. She was adamant her mom had already been through enough and seen too much in her life. She did not want her mom there on top of everything else her mom had lived.

But with Wednesday morning starting the same as Monday and

Tuesday, regardless of Deb's commandment, I picked up the phone and called Mom. I shared the updates and that she and Dad needed to come as soon as possible.

When Mom and Dad walked into the bedroom later that afternoon, Deb had not awakened all day long. Ken was a big man with a big, booming voice. He walked over to her bedside with a large bag of the pastries Deb loved from Panera and in his Dad rumble said, "Hey there, daughter, look what I brought ya, all your favorites from Panera and here you are sleeping."

Suddenly, Deb's eyes opened wide and she reached up and gave Ken a hug. "Well hey there, Dad," she said in a weak voice. "Yeah, I've been dreaming about some of that shit."

Deb looked over and saw her mom at the foot of her bed and euphorically waved her over. While they hugged, Dad laid out all the pastries. Deb was beaming as she tried for several minutes to pick the one she wanted. I marveled again how very quickly we had received the gift of having Deb back for that time. She finally settled where I knew she would end up, the cherry pastry. Then she looked up at me.

"How's that chicken doing?"

I don't recall what I had planned, but I know it was not chicken. "What chicken are you talking about, Baby?"

"You know that chicken we talked about that you put in the oven with the stuff on it? You told me earlier you were making it for me."

I had no idea what Deb was talking about. "Babe, you mean my barbecue chicken in the oven?"

"Yeah, you know the stuff you told me you were going to make me."

If Deb was willing to eat, I was more than ready to get cracking. Deciding it was faster to get fresh than thawing, especially with the grocery nearby, I made my run. Mom and Dad continued with their visit. When I returned, the boys were out of school and everyone was gathered in the bedroom around Deb. I was so relieved and thankful she, and we, were blessed with those precious moments of consciousness with a smiling Deb in no pain.

By the time I had dinner cooked and on a plate in front of Deb, she was starting to lapse in and out a bit more. I could only get a couple of bites in her, even resorting to trying to playfully tease her with the voice we had used with our sons when they were babies to coax a few more bites from her. Everyone sat in the bedroom with Deb for hours until Deb was nodding off more and everyone started getting tired. I walked over to Deb and kissed her and told her she had some folks who also wanted to kiss her and say goodnight. She reached up with her eyes barely open and put her hands on each side of my face and pulled me closer toward her. She was softly muttering.

"I love you, Baby. I love our boys. I love my Cody-bear but I'm so tired."

She pulled me down to her lips, kissing me. She continued for some time squeezing my face in her hands and kissing me and kissing me, holding me tight to her lips. With Deb so tired and others in line behind me, what I did and said next ripped me apart the rest of the night and will for the rest of my life.

I stopped kissing Deb. "Baby, don't you remember? You already kissed me so many times."

After everyone got their kisses, hugs, and goodnights in, with Deb and me, I walked back over to Deb's bedside, bending down.

"Hey Baby, now, how about some more of those kisses?"

But Deb did not respond. She was now in a semiconscious state, continually muttering softly. Words were coming out but they were gibberish. I sat on the side of the bed holding her hand for some time trying to get her to respond to me. Gradually Deb's mumbling became loud murmuring. I continued trying to talk to her for what seemed hours until my back hurt sitting on the side of the bed. I desperately wanted another moment like hours earlier, when suddenly Deb had sprung to life at the sound of Ken's voice. Hoping she was in there and listening to me, I begged and pleaded with Deb to come back.

"Please wake up."

"Please talk to me again."

"Please hold me again."

"Please kiss me again."

I grew more despondent and sorrowfully furious with myself for having unselfishly stopped kissing Deb so others could. If ever there was a time in my life I should have been selfish, it was then. I should have never removed my lips from hers. I realized too late, looking down at Deb, she knew what I didn’t want to. I was so determined to somehow wake her out of this, never wanting there to ever be an “our last kiss.”

I finally sat in my chair, as Deb’s loud muttering persisted. I continued to feel as if she was in there trying to talk to me. Somehow, her words were just not coming out correctly. She was still in there. She had to be, and she was trying to talk to me. I picked up Dr. Nuland’s book searching for another answer, an explanation. Befittingly, I flipped to the end, yet not wanting to read again the scribed prophecy unfolding in front of me. I could no longer read anymore.

An enlightened fool often remains a fool even with enlightenment. I just did not want to believe what I was reading even as I was seeing it. Yet, clearly, everything happening to Deb was doing so according to God’s plan.

At almost that exact moment, I looked up at the muted TV to see there was a new Clint Eastwood movie on cable just starting. The only thing I knew about *Million Dollar Baby* was that it won many awards. I thought that must be a sign, one of my lifetime heroes sending me a message.

“Endeavor to persevere.”

One of my fondest childhood memories is when I was twelve. My dad had just returned from one of his tours in Vietnam. He took me to see the new Clint Eastwood movie, *Hang ’Em High*, at the base theater. The private or lower-ranked enlisted who was working the booth tried to tell Dad he could not take his twelve-year-old boy into a mature movie even if he was a sergeant. Without any hesitation, Dad whipped around that booth and got inches from that soldier's face. I’m not certain what Dad said, but the next thing I knew, I was proudly sitting in the seat next to my dad eating popcorn. Clint Eastwood movies became a special bond for the rest of our life.

Alternating glances between Deb and the TV, I was not able to even half-escape into the story Clint Eastwood was weaving. But as the story progressed, I realized I had unleashed a nightmarish boomerang in the click of the remote. Everything that Clint Eastwood (Frank) was going through after Hillary Swank (Maggie) broke her neck was horrifyingly real, and not on the big screen but in my life and in my bedroom.

I had been living all the same stages Frank did—denial, anger, and begging God to take me and not Deb. I would do anything, "if!" Mere days before, I was in Frank's shoes. Deb was in the role of Maggie, repeatedly begging that I end her life. I didn't want to keep watching. But I could not make myself stop. That was the first and last time I will ever watch that Clint Eastwood movie. I was left agonizingly trying to get Deb to answer me. Over hours, I tried and tried, and then tried again.

Now the early morning of January 26, I devastatingly crawled in bed next to Deb. She continued talking to herself in muddled words that seemed hypnotic and trapped within. I tried to stay awake and did not want to close my eyes for a minute. I remember putting on the local early morning news. But the next thing I remember was waking to light streaming into the windows.

Triumphant Arrival

It was a little before 9:00 a.m. Except for the low volume of the TV, the room was hauntingly still. Deb was silent. I got up on my elbow and looked down at her. Her right eye was completely closed but her left eye was opened just enough of a crack that I could still see a sliver of her blue eye. I put my hand on her chest and could feel her taking short, fast, small breaths. I tried to talk to her and see if she would stir. But she did not move, except for the slow, shallow, rhythmic movement of her breathing

Over the hour as I lay there watching her, Deb's breathing started to change. Her breaths gradually got fewer and longer in between. It then became difficult to see if she was even breathing but I thought I could still feel the slightest movement of her chest. I got up and laid my head on her chest, trying to listen for a heartbeat. All I heard was dreadful silence. Her chest was now totally still. Startled, I sat up, looking at the clock, and it was 10:10 a.m. I almost grabbed my stethoscope, looking down at Deb. But I knew she was peacefully gone. There was no more pain. There was no more suffering. Deb could finally rest.

Cody never budged throughout the night or even then. He had silently been lying at the bottom of the bed with his head on Deb's leg. With a sadness reflecting knowledge, Cody kept his head on Deb's leg, looking up at me with sorrowful eyes. I called Cody over to my side of the bed. I hugged him and told him how sorry I was we had to lose her. I got up and Cody lay back down close to Deb and rested his head back on top of her. Looking down at Deb and Cody, I called hospice and shared what occurred and we needed Nurse Nancy straight away. Holding my heart in my hand, I walked over and opened the bedroom door. In a moment of eerie family ESP, perhaps the way of things, Mom was on the phone talking to Ray, updating him on his mom. They both heard the news at the same time.

Mom and Dad joined me in the bedroom and we gathered around Deb, hugging each other and her. Dad and I left after a while so Mom could have some time alone with her daughter while we waited for Nurse Nancy. Once Deb was officially pronounced deceased, I called the cremation service I had hired. As Dad and I paced around the front room, exchanging hugs, Nurse Nancy and Mom gave Deb her final bath. They put Deb's pale-blue silk pajamas on her she had gotten for Christmas and had never had the opportunity to wear.

To say we were disappointed doesn't cover the shock of the cremation service only sending one person to care for Deb's body. Once again and for the final time, our nemesis, the bedroom door, and that alcove were determined to have a final say. The stretcher was large and heavy and there was no way of even getting it partially around the alcove by our bedroom door. The mortician was perplexed. He made a self-defensive comment that no one told him he was picking up, "such a large woman," or he would've bought a backup.

Our only option was to get Deb out of the bedroom on a sheet. With Dad and Nurse Nancy on one side, and me and the mortician on the other, we lifted Deb and started toward the evil door. Dad and Nurse Nancy made it through the door and around the alcove. As we continued forward, we almost made it when the mortician slightly caught his elbow on the inside corner of the alcove and lost his grip.

The sudden downward force on the sheet caused Nurse Nancy to also lose her grip.

Deb hit the floor with a hard thud. I was horrified. I could not believe this was happening to start with. But to see Deb lying there on the floor took everything I had within me to keep moving forward to get her off that floor. We got Deb into the stretcher and with the mortician in the front and me in the back, we took Deb out the front door. The last thing I remember clearly seeing was the bottoms of Deb's feet sticking out from underneath the blanket that was covering her as the van doors closed. I watched as the van slowly pulled away and as with the evening Dr. Elizabeth was there, stood at the end of the driveway watching the rear of the van slowly disappear.

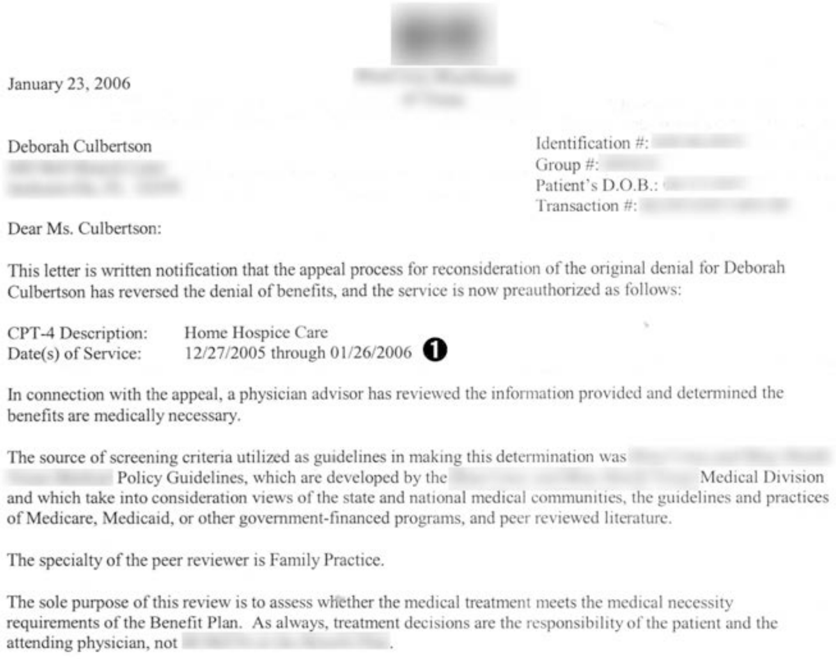
Mom, Dad, and I spent a soulful day calling family. We alternated between consoling those on the phone and consoling each other. Cody had spent much of the day in the backyard, and once inside, paced around each room and walked to the front door only to pace back in the bedroom again. Very unsettled, I choose not to take Cody for my most solemn walk.

I decided I did not want the boys to walk in the house and get the news that way. I slowly made the half-mile walk to the bus stop and waited. Thomas and Steven filed out of a long line of teenagers getting off the bus. They walked over to me with their heads down. Steven and Thomas already knew. They shared as they were getting off the bus, they looked over and saw me standing there without Cody and just knew. We hugged and I put my arm around them as we slowly walked home.

I had been telling them for some time and then repeated, everything was going to be OK. We were survivors and we would survive. As much as I was telling them that, however, they made me feel and know it during that long walk home. I was singing to the tried-and-true members of the survivors' choir. They never shed a tear and remained steely and stoic, even when hugging their grandparents after walking in the house for the first time without their mom, never to be again.

After dinner, I took another long walk. This time I did so with Deb's Cody-bear. I wondered how he would adjust. Even given my big speech to the boys, I wondered how we all would adjust and move forward. I don't know why I did it, perhaps the force of habit or having been on automatic pilot for so long. But after the walk, I stopped and pulled the mail out of the box on our way in. There was a letter from my insurance company. It was the last stab upon many into my heart and soul.

On the day I would lose Deb, I received a notice from the insurance company after almost a month of battling them, trying desperately, even as we had lived all we had during that month, to prove Deb's hospice care as medically necessary, and wondering what we would've ever done without hospice care and all the medications they provided without all the arguments, pre-authorizations, and delay. What would we have done without Nurse Nancy and the other nurses and those on the hospice 911 line?



[redacted]

January 23, 2006

Deborah Culbertson
[redacted]

Identification #: [redacted]
Group #: [redacted]
Patient's D.O.B.: [redacted]
Transaction #: [redacted]

Dear Ms. Culbertson:

This letter is written notification that the appeal process for reconsideration of the original denial for Deborah Culbertson has reversed the denial of benefits, and the service is now preauthorized as follows:

CPT-4 Description: Home Hospice Care
Date(s) of Service: 12/27/2005 through 01/26/2006 ❶

In connection with the appeal, a physician advisor has reviewed the information provided and determined the benefits are medically necessary.

The source of screening criteria utilized as guidelines in making this determination was [redacted] Policy Guidelines, which are developed by the [redacted] Medical Division and which take into consideration views of the state and national medical communities, the guidelines and practices of Medicare, Medicaid, or other government-financed programs, and peer reviewed literature.

The specialty of the peer reviewer is Family Practice.

The sole purpose of this review is to assess whether the medical treatment meets the medical necessity requirements of the Benefit Plan. As always, treatment decisions are the responsibility of the patient and the attending physician, not [redacted].

***Learning Opportunity**: ❶ I spent the last month of my wife's life fighting with the insurance company to approve Deb's hospice care. I only partially succeeded as they would only approve thirty days. Had Deb not passed away on the very last day of her insurance company hospice care approval, January 26, 2006, I would have had to begin the battle with the insurance company ALL OVER again, <u>the next day!</u>.*

Thirty days ago, some bureaucrat seated behind a desk somewhere determined despite what Deb's doctors diagnosed and prescribed, none of that was medically necessary. Thirty agonizing days later, another bureaucrat sitting at another desk, not in a doctor's office, decided to only authorize the previous thirty days of hospice care to end that very day, January 26. As if somehow, Deb was magically going to get better and no longer need hospice care? Or perhaps the insurance company used their care crystal ball to determine the last day they needed to approve Deb's care would be her last?

It was not just Cody among our furry extended family who knew Deb was gone. Our gray cat Smokey, who for years spent at least two-thirds of his time outside, uncharacteristically insisted on coming in the house. When I went to bed that evening, my first time lying in Deb's fancy bed knowing she would never be in it again, Cody had his furry buddy in the bed with him. Smokey never got on the bed, but there he was, eerily lying on Deb's side of the bed near Cody.

I don't know what time I finally passed out. During the night, I was awakened by snoring. I instinctively rolled over and put my arm around that which was snoring, absolutely believing it was Deb. As I lay there slowly waking and listening, I suddenly realized it was not Deb I had my arm around. It was Cody. He was not in his normal position at the bottom of Deb's side of the bed. He was on his side spread out with his back to me. He had his head on Deb's pillow lying closely next to me. I had finally awakened to realize all this was not a bad dream, but a difficult new alternate reality.

It was precisely in that moment I also realized why Deb was so insistent on getting Cody so quickly after Mich died. She knew this day would come and she knew I would need him. As much as she mothered him, she had not gotten him for her. Deb had placed him in our lives for me. Deb had gotten Cody for this night and those times ahead. Comforted by his presence, I held Cody close and snuggled up next to him ever so tightly, resting my head on his shoulder as I drifted back off to sleep.

In what I thought could have only occurred in animal lore, for three days and three nights, Smokey stayed glued to Deb's side of the bed. Finally, after the third day, he wanted back outside. That would be the last time Smokey would ever walk back into our home. Thereafter, the boys and I could never coax him inside. For years, we kept his food and water outside until one day he finally just disappeared, never to be seen again.

Deb's desire was to have her ashes placed at the beach park where we had been married, along with Mich's ashes we had solemnly saved for this occasion. On February 12, 2006, over 120 friends, family, and many of my healthcare colleagues made the journey. They knew of Deb as I had used all that you have read as ammunition for our change healthcare initiatives. Some were in New Orleans and had welcomed Thomas and Steven into our workgroup and our adventures.

Mr. Bill; my longtime business associate and friend, Peter; and his wife, Pam; and my closest colleague and dearest friend, Sue; and husband, Terry, from Boston were among the dear gathering. Sue had continued to send Deb a postcard every day of Deb's war, adorned with one of her special photographs—five years' worth of daily heartfulness. I could not imagine what it was going to be like without seeing those arriving in the mail each day and placing them into Deb's hand.

My dad had organized the food effort with my mom, four sisters, Cathy–Brenda–Terry–Robin, and my brother, Mike, as well as their spouses, and many of my cousins. It is our family way. We do not cater. Together we lovingly make meals for family gatherings, happy and triumphant holidays and graduations, or those deeply saddening and mournful.

We had everything planned. The pavilion where we would hold our gathering, as we had there over so many years. Nearby was the little wooden bridge crossing the inlet leading into the lagoon where Deb and I were married on the other side. But in holding such a gathering, we had defied Deb's decree. She had already sternly warned she did not want anyone crying over her or a big to-do and sendoff. Even from above, Deb once again tried to take charge. In collaboration with God, they delivered a beautiful, perfectly sunny day. Only it was the coldest day of the year at thirty-seven degrees and blustery off the water. Deb did everything she could to chase everyone away, but she did not succeed. While from the attendees to the food everything quickly chilled, everyone warmly huddled and hugged in place.

For Deb's ceremony that she did not want, despite her displeasure over the years at receiving roses because she hated to see them die, I had gotten a red rose for every person that had attended. I walked among the crowd with white roses in hand. I started at the beginning of our life together, all the way to Deb's end. I picked out those in the gathering who in some special way, family, friend, or colleague, had an impact on our life. Without shedding a tear and remaining serenely calm, I walked up to each person, handed them a white rose, and shared with everybody in attendance how that person was special in our life. I handed out many white roses and I took much time to accomplish this.

When I was done, and others had their say, I saw nothing but wet eyes about me among the sorrowful sobbing. But I noticed after my difficult soliloquy as I had looked at them first and now last, in addition to my dry eyes, there were three other sets—Thomas, Steven, and Ray. We stayed strong for each other as we walked down to the little wooden bridge overlooking our lagoon. Deb wanted us to put Mich's ashes saved for this solemn occasion in the water first so he would catch her. Her boys and I bent down as the tide was coming in. We watched as Deb joined Mich in the water. Moving slowly with the tide, they started swimming together into the lagoon toward the beach on the other side where we had been married.

The boys and I hugged each other and placed our roses in the water, as many others did after us. The most beautiful sight I will ever live to see was walking back down to Deb's bridge by myself just before we left. Others visiting the park on that cold southern day had also gathered on Deb's bridge, staring.

I quickly became among those mesmerized by the beauty of it all. Standing on the bridge looking across to the spot where we wed in the middle of so much overwhelming heartbreak and pain. Yet looking into Deb's lagoon, I suddenly felt a rush of warmth and serenity. A breathtaking sea of red and white roses was spreading and flowing all about the lagoon. Each rose, triumphantly heralding Deb's peaceful arrival

Epilogue

After we returned from Deb's memorial, our sons and her Cody-bear walked about, in silent surrealism, a home left without her. Even though we were not alone, we were alone. My parents, Walt Sr. and Rita, and my Uncle Cal and Aunt Charlotte from Baltimore stayed through a Valentine's Day not celebrated and then to be with me on my fiftieth birthday, days after we laid Deb to rest.

We then set forth in our initial steps forward on the foundation in which we stood. Starting with new colors for the inside of the house. My uncle and aunt stayed for most of the rest of February 2006 helping us in our quest. During that time, there were no tears. In fact, at the behest of Uncle Cal and his shenanigans, there was at times laughter and lightheartedness that took the edge off our solemn feelings of loss and grief.

By day, while the boys were in school, Uncle Cal, Aunt Charlotte, and I engaged in what I can only describe as painting therapy. We painted and painted and painted, every room in the house from top to bottom with some rooms adorned in bright shades of blue to match the whites, tans, and creams in other rooms. Puffy and his pals in the aquarium peered on in amusement as Uncle Cal and I laid a bright blue color on the wall behind them and around the nook. Even Cody appeared perplexed as the new blue went up on the wall behind the bed.

Having my family there with the boys and me through that first month, kept us busy erecting the foundations for a bridge that would help us move across what could have been a formidable canyon otherwise. With the remodeling completed and out of more ideas and projects to delay the inevitable, the wistful day arrived for my aunt and uncle to finally return to Baltimore after almost a month away.

Regrettably knowledgeable of such things, I once again sought counsel from my rock and anchor, Jeanne. What remained in front of me was perhaps my most difficult step forward: what to do about Deb's closet full of clothes and things. With Mom's strength and the help of Deb's sister Vicky, we spent several days in the closet organizing what was being affectionately shared with family and what would be donated to our hospice heroes and the local women's crisis center Deb and I supported. I was thankful Deb would continue to live on and touch others through her beautiful things.

During those first months of transition and beyond, my sons and I continued to doggedly carry on, doing what each needed in order to pick up the pieces and move on with our lives. Watching and listening to Thomas and Steven, and how quickly they adjusted, was not just inspirational, but much needed wind within once-stalled sails. Together, we worked our way into what became, "our new normal."

Cody as well figured out his new normal. Slowly over the weeks, he moped about less and less. As Cody had been affixed to Deb's hip, he was now glued to mine. The nightly routine of sleeping in Deb's spot on the bed with his head on her pillow became part of our new normal. We got out of the house more, including to the beach. Most weekends we could be found hanging out at Mr. Bill's for Saturday grillin', chillin' and swimmin'. Cody developed a great reverence for Bill's pool. As if a waterlogged child refusing to get out, Cody never went quietly into the night or into the back of the Pacifica when it was time to go home.

One month after losing Deb, I had another big step along the path to a new normal. It was time for me to get back to work and equally work on resolving my financial situation. At age fifty, I was starting over again deeply in debt. But I also knew I was among the more fortunate of my fellow Americans. I possessed skills and a lifetime of experience using them. I had stopped accepting contracts during the late spring of 2005 after Deb became my full-time job, so I was ready to get back at it.

I had made the determination to focus on paying off the hospital, but only pay the medical center $100 a month towards my almost

$22,000 debt with them. In my logic, they were the reasons I was staring at a mountain of debt right alongside our fickle "one minute you're in network, the next minute you're not," healthcare roulette system. Devoting most of the proceeds from my consulting income, I worked over the next year to completely pay off all the hospital charges. Even though the clinic continued to add charges to my wife's bill, more than a year after her loss, at $100 at a time, I still reduced the medical center bill to just under $20,000.

STATEMENT NUMBER: 3476408
P/C L

SHOW AMOUNT PAID HERE $ ______

OFFICE PHONE NUMBER	CLOSING DATE	GUARANTOR NUMBER	PAGE NO.	NEW BALANCE PAY THIS AMOUNT
[redacted]	❶ 02/10/07	[redacted]	01	210.00

DEBORAH R CULBERTSON
[redacted]

[redacted] CLINIC [redacted]
[redacted]

NOTE: Charges and payments not appearing on this statement will appear on next month's statement.

00000031 [redacted]

CHARGES APPEARING ON THIS STATEMENT ARE **NOT** INCLUDED ON ANY HOSPITAL BILL OR STATEMENT

DATE	PROVIDER	DESCRIPTION	BILLED TO INSURANCE	PATIENT RESPONSIBILITY
		Previous Balance	210.00	
		DEBORAH CULBERTSON [redacted]		
	[redacted] CLINIC [redacted]			
		Adjustment(s)		
020907	0001	PATIENT RESPONSIBILITY	-210.00	
		*** THE FOLLOWING CLAIM(S) HAVE BEEN *** * PROCESSED SINCE YOUR LAST STATEMENT. * * *		
091905	[redacted] ❷	*OMNIPAQUE 300 - 100ML*	*84.00*	
092305		*OMNIPAQUE 300 - 150ML*	*126.00*	
020907		PATIENT RESPONSIBILITY		210.00

STATEMENT CLOSING DATE: 02/10/07 PLEASE INDICATE YOUR GUARANTOR NUMBER WHEN CALLING OUR OFFICE: [redacted]

BALANCE FORWARD	PAYMENTS	CREDITS	CHARGES	NEW BALANCE PAY THIS AMOUNT
.00			210.00	❶ 210.00

***Learning Opportunity**: ❶ Only in America, can a husband who lost his wife thirteen months prior, still be getting bills in the mail for his late wife's care. ❷ In this case, for services rendered over seventeen months prior to the statement date.*

Every month as I wrote that $100 check, I waited for the inevitable call and showdown with the billing office of the medical center. This was one of the sources of Deb's greatest fears and anxieties. Every month after Deb was gone, as I wrote that check, often with hands shaking, I felt every moment of all those moments with Deb. I wrote the check and I waited.

To my shock, in April 2007, a few weeks after discussing surprise medical billing/debt on a local cable TV show, I received another billing surprise. Instead of my normal billing statement, I had to look at this one countless times to make certain I was reading what I thought I was reading. The medical center completely wrote off the rest of Deb's medical bill.

STATEMENT NUMBER: [redacted]
P/C N

SHOW AMOUNT PAID HERE $ ______

OFFICE PHONE NUMBER: [redacted]
CLOSING DATE: 04/07/07
GUARANTOR NUMBER: [redacted]
PAGE NO. 01
NEW BALANCE PAY THIS AMOUNT

DEBORAH R CULBERTSON
[redacted]

[redacted] CLINIC [redacted]
[redacted]

NOTE: Charges and payments not appearing on this statement will appear on next month's statement.

0000003[redacted]0000000004[redacted]

CHARGES APPEARING ON THIS STATEMENT ARE **NOT** INCLUDED ON ANY HOSPITAL BILL OR STATEMENT

DATE	PROVIDER	DESCRIPTION	BILLED TO INSURANCE	PATIENT RESPONSIBILITY
		Previous Balance		19488.51
		DEBORAH CULBERTSON [redacted]		
	[redacted] CLINIC [redacted]			
		Adjustment(s)		
040606	0001	DEBIT-MISCELLANEOUS -CORRECTED		-20399.67
040606	0001	DEBIT-MISCELLANEOUS		20609.67
032107	0001	ADJUSTMENT-PROBATE		-19698.51

STATEMENT CLOSING DATE: 04/07/07
PLEASE INDICATE YOUR GUARANTOR NUMBER WHEN CALLING OUR OFFICE: [redacted]

BALANCE FORWARD	PAYMENTS	CREDITS	CHARGES	NEW BALANCE PAY THIS AMOUNT
19,488.51		-40,098.18	20,609.67	❶ .00

***Learning Opportunity**: ❶ NEVER GIVE UP! Become your own best care advocate!*

I vividly recall sitting in our screen room with a Crown in one hand and petting Deb's Cody-bear with the other that evening. I should have been elated, but I just sat for hours incomprehensively staring at that statement, then out at the woods behind our home. Trying to reconcile how it all had happened. How it all suddenly ended. A treacherous healthcare journey, while now concluded, would never truly be over. After five years of the battle and all Deb had endured, the remnants of the costly war were tragically too many heartbreaking moments followed by a sudden jarring of unrelenting silence.

Thomas and Steven would go on to prove their mother correct, getting their degrees in technology. Deb did indeed spawn what she lovingly called her "computer nerds!" Deb did, however, get the count wrong. Ray has an equally impressive technology career, much of it in healthcare! I am a blessed dad who continues to be amazed and inspired by his sons.

In the years since losing Deb, I have also been fortunate to have witnessed the everlasting spring of evolution through Deb's intelligent and heartful sons and the beautiful granddaughters she sadly would never meet. I see and hear so much of Deb in Mackenzie, Piper, and Kendall. I have thankfully been blessed to have lived to see materialize what Deb and I happily shared with each other after Ray and Susan departed from that first and last time Susan would meet Deb.

"Separately, either one is going to significantly succeed."

"But, together they're a dynamic duo, destined to soar to great heights in every aspect of their lives."

Deb would be equally pleased and overjoyed to meet Courtney, Steven's wife. Beautiful, warm, intelligent, and as with Ray, Steven found his soulmate and match made in heaven. I am blessed to live near them and have had many adventures with my wonderful son and daughter, whom I not only so love and adore, but as well deeply respect. As Steven and Courtney hear more often than not these days, I also look forward to the next grandchild, but no pressure or anything!

Deb would not be surprised that Thomas is still these days, heads down in his career, following perhaps too much so in his father's footsteps as a chip-off-the-old-block night owl, fully engaged in his talent and love of designing programs and implementing systems. Although Deb would be surprised that, unlike his old man, Thomas is not allergic to a hammer and a screwdriver and is doing a masterful job remodeling his home.

As for me, I was never able to go back to the career I had prior to Deb getting sick. There have been many times over the last fourteen years, I wished to God I could have just walked away from healthcare and crawled into the comfortable and simple life of cranking code and systems. But I just could not turn a blind eye to our ever-increasing and getting worse inequitable mess and confusion that is Healthcare in America. I started down a path I still wander today, selecting projects and causes for the opportunity to make change in healthcare, rather than just putting change in my pocket at the expense of healthcare.

With a burning desire to help prevent prescribing errors, in November 2006, ten months after Deb passed, I was honored to become the Founding Executive Director of an electronic prescribing initiative. Our physician outreach presentations concluded with a "*Why We Are Here*" slide containing only that picture of Deb's admitting and morphine allergy bracelets, and the prescription for morphine written for Deb while she wore both those bracelets. Over the next three years, we helped propel our state from twenty-fifth in the nation in the physicians' use of electronic prescribing to tenth in the nation.

From there, I helped start up and lead our state's largest federally funded physician electronic health record (EHR) adoption and training program. But I also had another burning desire, to help fix what had also bedeviled Deb—the right information being at the right time to the right person. I went on to proudly help build and lead our state's effort to create a statewide Health Information Exchange (HIE) connecting hospitals, doctors, and other healthcare stakeholders to securely exchange and make available patient records.

Today, my burning desire and focus is you. Even those of you who have not been labeled yet or have had frequent encounters with what we have for a healthcare roulette system. One day you shall. Often when you least expect it or have planned for it. Out of the blue and in the space of time it takes to be on the other end of two words coming from a doctor.

"I'm sorry!"

Most especially if you are as Deb was, suddenly and jarringly thrust into the middle of the battle of your life—standing up to cancer.