

# EXPERTS<sup>TM</sup> 2019 BY EXPERIENCE

*Patient stories that teach*



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# Foreword

Welcome to our second eBook, “Experts by Experience—Patient Stories That Teach,” a collaboration of Mayo Clinic and Inspire.

Never before have doctors had the science, knowledge or technology that they have today to diagnose and treat diseases. Yet, patient experience remains at the heart of good health care delivery. When patients and caregivers share their lived experiences through stories, providers gain insights into the patients’ needs, their beliefs and concerns. This knowledge can help health care professionals foster patient engagement and communication, and facilitate care decisions with patients as partners—all of which can go a long way towards healing.

The 2020 eBook, comprised of 24 articles written by patients and caregivers and published on the Mayo Clinic Social Media Network blog in 2019, is the capstone of this two-year Mayo Clinic/Inspire collaboration. We look forward to new collaborations in 2020 and beyond.

The main motivation behind our starting the Experts by Experience series was to bring the patient perspective to those who can learn from these experiences—particularly health care providers, and those in health communication and administration. We have succeeded in bringing these perspectives to millions of readers worldwide, and for that we are proud, and grateful to all the Experts who contributed to this series.

Brian Loew, Founder/CEO, Inspire



Farris Timimi, MD, Medical Director, Mayo Clinic Social Media Network



# About

[Mayo Clinic Connect](#) is an online community, connecting patients and family caregivers with each other. Community members share experiences, ask questions, find answers, give and get support and exchange vital information. Mayo Clinic values patient and caregiver knowledge and recognizes them as #ExpertsByExperience.

[Mayo Clinic Social Media Network \(MCSMN\)](#) was established in 2010 to improve health globally by enhancing the use of social networking tools throughout Mayo Clinic and by gathering a collaborative learning community of those interested in applying social media in health care. Members include hospitals, healthcare communications professionals, and medical providers, as well as patients and caregivers from around the world.

[Inspire](#) is the leading healthcare social network, with a mission to accelerate medical progress through a world of connected patients. Partnering with over 100 nonprofit patient advocacy organizations, including the American Lung Association, Ovarian Cancer Research Alliance, Bladder Cancer Advocacy Network, and the Lupus Foundation of America, Inspire creates and manages support communities for more than two million patients and caregivers.

*Experts by Experience 2019: Patient stories that teach* editorial team: Lee Aase, Gregory Kolen, John Novack, Kanaaz Pereira, Eric Taylor, Farris Timimi, MD, Melissa Tsai, Colleen Young

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# Threads of Connection

By Amy Camie

Everything we do creates energetic, invisible links joining us together—threads of connection. Be it a smile, a gentle touch, or a grumpy mood, our feelings affect those around us. And whether you're a medical professional, service provider, patient, or caregiver, you have the power to transform any health care encounter into one of comfortable, compassionate care.

For years I played harp in hospital waiting rooms, patient rooms, and chemotherapy infusion units to help ease anxiety, lull patients to sleep, and provide a gentle distraction from ongoing treatments. There were times, in the infusion units, when I remember thinking, "How could they just sit there and allow that poison to be pumped into their bodies?" I had no personal experience with chemotherapy, and could only imagine how I would react in the same situation. Recognizing that my personal assumptions were not supportive to the space, I'd take a deep breath, re-center myself, focus on the love I was sharing through music, and continue playing.

Several years later, I experienced two separate breast cancer diagnoses and my judgments from the past quickly dissolved. As I made choices that were previously unimaginable, a deep feeling of empathy emerged for those patients who had once enjoyed my music. My old beliefs and perceptions started to crumble with the awakening of new inner strength and self-compassion. The energetic threads of connection from those surrounding me offered comfort and support when my body, mind, and



spirit felt like porous sponges after treatments. Every day was a different experience—"normal" did not exist as I learned to dance with all the details: appointments, tests, new medications, and side effects from treatments.

These insights from my two journeys with breast cancer supported my recent role as a patient advocate and co-caregiver for my mom when my father had complications after open heart surgery. During his first nine days in ICU, my siblings and I were extra attentive to our mom's emotional state. In preparation for what we knew would be a long journey ahead, we all agreed to help each other remember basic self-care needs to maintain some consistency—drink water, go to the cafeteria for one warm meal a day, keep an extra book or magazine handy, create group texts so friends and family can be



updated, encourage as much sleep as possible. Dad's medical team took extra time to explain how they were treating each number on his monitors. It may seem trivial, but understanding how his cardiac index was directly related to his hydration levels felt empowering and offered us a purposeful way to focus our energy.

For the most part, those caring for my father brought us a sense of peace with their focused confidence, patience, and precision; each person became an individual thread, weaving their unique role into our family's blanket of experience.

One nurse, a self-proclaimed ADD sufferer, blew into my father's room one night like a tornado. She spewed unwanted comments and frenetic energy all over our soft sacred space. Although she was very competent, her unintentional jokes about not knowing what to do next with my

father's medications triggered feelings of panic in our exhausted mother. When I spoke up and asked the nurse to please be more aware of how her words and actions were affecting all of us, she looked surprised and apologized. From that moment on she was more considerate and calmer.

My message to healthcare professionals is this: Treating patients is your daily routine. Please walk gently, speak softly, and be patient with us as we navigate our new experiences. The value of being aware of the energetic threads of connection with those around us is simply to become more conscious of how we choose to be in relationship with each other; a choice that can turn a frightening experience into one of compassionate care.

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Please walk gently, speak softly, and be patient with us as we navigate our new experiences.

**Amy Camie** is a professional harpist, recording artist, composer, public speaker, and author of *"Loving Life...All of It—A Walk with Cancer, Compassion, and Consciousness."* Her solo harp CDs have been used in several pilot studies indicating how they increase neurological functioning, support the immune system and reduce pain, distress and anxiety levels. Her Facebook page, [Facebook.com/AmyCamieHarpist](https://www.facebook.com/AmyCamieHarpist) includes many videos and inspirational posts. For more information, [AmyCamie.com](http://AmyCamie.com) or find her on Twitter at [@AmyCamieHarp](https://twitter.com/AmyCamieHarp).

# How Cancer Opened New Doors for Me

By John Fisher

**A**t the age of 42, with my wife who was not quite 40 yet, we had become used to the questions that couples without children get from family, friends, and strangers. We were at peace and confident in our decision to remain childless. Of course, without a prostate, that decision was as final as could be.

About four years ago, doctors found a quarter-sized tumor, malignant and deeply embedded, in the wall of my bladder which simply could not be removed. I learned quickly that once high-grade bladder cancer (urothelial carcinoma) invades the muscle wall, there is very little one can do to prevent it from coming back again.

Any kind of malignancy is an ordeal, but I was to have one of the most oft-utilized organs in my body completely removed and replaced with a new urinary diversion, which presented a whole different set of decisions. And, my prostate would not be spared if I wanted to get out of this with a chance to be cancer-free.

My wife's role turned to that of a caregiver long before any surgical procedures were scheduled. Justified anxiety and a tendency to worry clouded my initial outlook. I turned to online articles spouting survival statistics (which have not changed for over 30 years), as well as the varying complications one could have whether they chose a new man-made bladder—a bag outside the body—or a relatively new diversion called the neobladder, where the urinary bladder is made out of your own intestinal tissue and



constructed to stay inside the body.

What really concerned me was how I responded to stress up to that time in my life. I had always been a highly anxious, worried boy who matured into a stressed-out young man, and ended up entering middle age with a few better coping skills—yet with the same old tendency of allowing worry to overtake me. Lo and behold! I surprised myself when the most crucial event of my health history had arrived. There I was, standing up to it, calmly researching it, educating myself, reaching out in online forums to others affected by bladder cancer. This, most definitely was not the “me” that I knew.

A key difference was a family counselor I had reached out to, for help with anxiety and depression through an employee assistance program a couple of years prior to the diagnosis. She introduced me to meditation



and other practices; she got through to me in a way that other professionals had not, especially when I was seeking help for anxiety in my 20s and 30s. More importantly, she listened a whole lot better than others.

I had also taken charge of my health by asking my hometown urologist for a referral to a nearby National Cancer Institute (NCI) designated hospital. Knowing I was in the care of one of the most respected urologists/oncologists in the country boosted my confidence and enabled me to own my diagnosis. I started to look for the positives in my decent physical condition, my relatively young age, and began building on those by pushing myself into optimal physical shape before surgery. The tumor produced no pain, or other symptoms, aside from hematuria—which had alerted me to the problem. I dove into research that focused on post-surgical rehabilitation and recovery, as well as all possible outcomes of surgery if things didn't go as planned.

Friends, family, and of course my wife, played an important role in holding me up—not only through the initial shock of my diagnosis, but the recurrence that would follow six months later, after my first post-surgery CT scan.

“I’m ever mindful of the possibility of recurrence and the unknown landscape of immunotherapy’s durability.”

Another lengthy, and now risky curative surgery, radiation therapy, and the decision to meet with a clinical trial doctor would follow. But with the support I received and the preparations I had made, I was able to keep my head through it all (except for a few “Why me?” moments).

Now, fortunately, due to an available clinical trial for nivolumab, I am enjoying remission. However, I’m ever mindful of the possibility of recurrence and the unknown landscape of immunotherapy’s durability after it has shrunk, stabilized, or eradicated metastasis.

I find myself living life as completely and fully as I did before but with a far different perspective on how to move forward confidently, and with disregard for paying attention to the “small stuff” when unwarranted.

In this way, the illness has probably improved my life, and that improvement includes the ability to get to know others—patients and caregivers who are also living through the maze and sometimes tragedy of cancer.

**John Fisher** is an information technology specialist in Cedar Rapids, IA, who has battled bladder cancer and metastatic bladder cancer for four years.

# One of a Kind: When Your Child has a Condition with No Name

By Bo Bigelow

**T**oday, I'm spending the day with my daughter, Tess. She's nine years old.

Since Tess's birth, my wife and I have drastically redefined our lives. We have simplified our working lives in order to make room for medical appointments, sessions with specialists, and educational meetings. We've connected with a group of diehard friends and relatives—people who we can call at any time, night or day, to ask for help. We've slowed our lives down to make days like today, possible.

You see, Tess has an ultra-rare disease. It is so rare that it doesn't have a name! We simply call it USP7, after the gene that shows the mutation. Because of that mutation, she's non-verbal, she has autism, epilepsy, vision issues, gastroenterological problems, and intellectual disability—even though she is nine years old, she functions at the level of a toddler.

It is dark and not quite 5 a.m. when we hear Tess calling to us from her bed. I go to her room and unzip the safety enclosure that fits over her mattress. Without it, she wouldn't be safe—she puts everything in her mouth, whether it's food or not. As a result, even her own room can endanger her. I pull her out, hug her tightly, and whisper, "Good morning." Excited to start the day, she hugs me back.

At breakfast, she uses a speech device to talk. Over and over again she repeats, "Eat. Oatmeal." I spoon it into her mouth—food is one of her



favorite things. In recent weeks she has started requesting other things—she has navigated to the button that indicates she needs to use the bathroom, she has said the word "up" and meant it. Such gains in communication have been slow and taken years of speech therapy. But we are thrilled!

Later, I take her to an indoor pool, where it's warm and no one else is there. She loves the water—actually, her favorite place to be is underwater. I used to have to hold her for the entire swim, but these days she fights me like crazy—she pushes my hands away, dunks her head, and cannot wait to swim on her own. After ten minutes, she becomes still and quiet.

Her face takes on a greenish tint, and I get her out of the water just in time for her to spit up a cup of pool water. She is getting better about closing her mouth and not swallowing water during her weekly swimming lessons, but she still has a lot to learn.

Our days have not always been as peaceful as today. It took years to get here. In the beginning, before she was diagnosed, we were so worried about losing Tess. We bounced from one medical appointment to another, in a healthcare system that isn't built to deal with USP7. My wife was made to feel like she was a "crazy doctor-mom".



*The author with his daughter*

One pediatrician even dismissed us, saying Tess's eyes were fine, although we knew she could not see. Only later did we learn how right we were—Tess has cortical visual impairment, so her eyes have trouble telling her brain what she sees.

Tess has also had some wonderful doctors. When we look at the best care she has received, there are two principles that stand out:

- Do not try to take our star-shaped child and fit her into the space meant for a circle. Instead, try to think about ways that would set her up for success.
- As her parents, we've spent time learning about her rare condition, so we are the experts on USP7—when we have questions, when we are concerned, please listen to us.

Tess is restless in the afternoon—I can tell she wants something, but I cannot figure out what it is she wants. Despite her progress with the speech device there are times when we don't know what she is trying to say. She's tired now, but does not want to sleep. She climbs into my lap, and with my cheek against her neck, I hum low notes into her ear. I've spent the whole day talking to her—narrating our activities, asking her questions, saying her name. Aside from some joyful yelling in the pool, she has remained silent. But this, the low vibrations of my humming, triggers a response from her. She lets out a tiny murmur, her shoulders relax, she leans against me, and melts in my arms. When I stop humming, she grabs my elbow—her way of saying, "Do that again."

**Bo Bigelow** lives in Maine with his wife and two children. He is Chairman of the [Foundation for USP7 Related Diseases](#). He is also a co-founder of [DISORDER: The Rare Disease Film Festival](#), and hosts the weekly podcast, [Stronger Every Day](#). You can find him on Twitter at [@bobigelow](#).

# Living Life on Pause

By Gabrielle Lopez, MPH

**March 2016**—a seemingly ordinary day, but I remember feeling that something wasn't quite right. Throughout the day I'd been nursing a headache, with no sign of relief. That evening, standing in my kitchen, I felt an explosion of pain inside my skull. The feeling was indescribable! I realized I needed help as thoughts came slowly while I tried to relay my distress to my three young children. I tried to speak but could not think of the words, and my mind felt suspended between two worlds. I was convinced this was the end, and I was going to die with my children watching. But I was wrong—it was not the end, but the beginning of a two-year battle to determine the cause of these terrifying symptoms.

Despite being admitted to hospital and extensive testing, I was discharged with no diagnosis. Weeks passed as I waited for referrals to specialists. I wasn't quite out of my thirties, and I spent my days confined to a recliner in my living room, physically weak and scared. There was no trace of the woman who used to enjoy swimming and hiking with family; my scalp burned for days at a time, and even a gentle hug from my children would leave me trembling with the sensation that my bones were breaking.

As the list of diagnoses and medications grew, so did my despair. While each specialist offered a piece of the puzzle, none could give me an answer to my most pressing question: "What is wrong with me?"



I spent a lot of time alone, thinking, during the seemingly endless wait between appointments. At first, grief trickled in and then became a deluge that threatened to drown me. Each time I thought I had accepted this new life, another diagnosis or medication would renew and restart the grieving process. What hurt most wasn't the physical pain, but the lies my mind would tell me while I was steeped in misery. Days slipped by, and saw my future drifting away.

When doctors asked how I was, feeling, I'd reply, "Fine." I didn't tell them about missing the countless events that I used to attend without a second thought. I didn't say that I felt incredible guilt and shame because I couldn't force my body into compliance. I never spoke what was on my mind...and no one probed to find out.

“What hurt most wasn’t the physical pain, but the lies my mind would tell me while I was steeped in misery.”

**2017**—I had half a page of diagnoses, but still felt that something was missing, and I decided to build a new care team. I sought recommendations from family and friends, combed through online reviews, scanned physician profiles. Finally, I selected a primary care physician who wrote that she enjoys “taking care of complex medical problems.” I felt an instant connection when we met for the first time in December 2017. It wasn’t her educational background or her thoroughness when she examined me, but her interest in me as a person and her willingness to include me in developing a treatment plan aligned with my goals, that made all the difference.

**2018**—Nearly six months into our relationship, the quality of my life improved greatly. While

I’m not able to run a 5k race, I can walk to the top of my street. The number of migraine days dropped from an average of seventeen per month to six, and the overall pain days have decreased to nearly half the number they used to be. A psychologist helps me sort through the feelings surrounding my chronic illness, and I’ve developed a strong support network of friends and family. In April I was referred to a geneticist to explore the possibility of Ehlers Danlos Syndrome.

I may not have the life I had planned, yet as I write this, I feel a strong sense of hope—that I will soon have an answer to my question, “What is wrong with me?”

**Gabrielle “Rie” Lopez**, holds a graduate degree in public health, with a specialty in health education and promotion. She is particularly interested in the intersection of chronic illness and mental health. After a health crisis, her experiences led her to start advocacy work in the chronic illness community. Rie is a health educator and serves as a patient advocate for mental health, chronic pain conditions, and clinical trials. You can find her on Twitter at [@RieOfLetters](#) or through her blog, *Rising Inside the Embers*.



# My Leaky Life: Learning to Live with Chronic CSF Leaks

By Rebecca Wallick

**M**y dogs and I prepare to head out for a walk in the forest. They're excited—which makes it challenging for me to put their visibility vests on them. My anger instantly swells out of proportion; I growl, move abruptly. The instant I'm short-tempered with them, I simultaneously recognize it and back down, asking myself, "Who are you and what did you do with Rebecca?"

This ability to analyze my behavior, in the moment, is the result of much practice. Over the past 15 years I've had to learn to control a temper I never used to have—a temper that's the by-product of a condition that for most of my life I also didn't know I had.

My twin birth defects of spina bifida occulta and a tethered spinal cord were discovered in 2002, following a hard fall while running trails. It took nine months, three neurologists, a spinal tap, two MRIs, and dogged persistence on my part to receive an accurate diagnosis for the horrible, months-long headaches, tinnitus, dizziness, fatigue, and brain fog: spontaneous intracranial hypotension caused by leakage of cerebral spinal fluid (CSF).

Because I kept running whenever I could, the first two neurologists didn't believe my headaches were bad enough to fit the CSF leak diagnosis; most patients can't tolerate being upright, let alone run. It was the third neurologist—a former endurance trail runner himself—who understood that running was



my coping mechanism and that, as an ultra-distance trail runner, I had high pain tolerance.

## Learning to Cope

After many cycles of CSF leaks—which I jokingly refer to as being a quart low—I can match the degree of the leak to personality changes that weren't initially obvious to me. My emotional reactions were something new. I was easily irritated, to a greater degree and much more quickly, by people I knew as well as by total strangers; by loud noises, traffic, computer glitches—basically by normal life. Before that fall in 2002 I was upbeat, with boundless energy for friends, work, activities, even chores, I now felt unmotivated and easily angered.

I've learned to anticipate the bad times, as well as situations and people who are triggers.



If unable to avoid them altogether, I stop my reaction pre- or mid-outburst with a mental “Chill!” that reminds me that the problem is me, not them. But it makes fitting in with cultural norms regarding work schedules and socializing challenging. I berate myself for not getting enough done, for sleeping too much, avoiding people...for not being me—the me I was before CSF leaks. Cutting myself enough slack to rest and heal with each new leak is tough!

### Changing to Cope

Almost unconsciously, I’ve crafted a lifestyle that accommodates my condition—one that puzzles family and friends. Abandoning a 20-year legal career, I left Seattle in 2005 to live on five acres in rural Idaho. I knew I needed space and quiet to escape having to cope with too-close neighbors or typical urban cacophony. I left cushy jobs with good benefits because dealing with co-workers, work schedules, and commuting was almost unbearable. I’m now self-employed, working from home, in charge of my own schedule. Most days I nap when “normal” people are taking a lunch break, which allows my CSF levels to recoup.



Rest and caffeine are the only treatment options that help. I shun most social situations, especially big, noisy gatherings.

### Running to Cope

I keep running, always with my dogs, who are my emotional therapists. The pounding is sometimes excruciating inside my head, but I run nonetheless—gently, less far, no longer racing—because it helps me cope. That runner’s high and sense of well-being are worth the extra pain. Running trails in the forest among trees, streams, wildflowers, and wildlife, and moving, no matter how slowly, keeps me sane. In those moments, I don’t feel disabled, I don’t think about pain. My creativity flows and I feel normal for a while.

Today I’m honest and open about my condition and its emotional impacts. I’m more stoic—taking each day as it comes, grateful for its gifts, not dwelling on the former “healthy” me. My dogs help defuse the stress of chronic pain while joining me in a lifestyle that accommodates my disability and makes me happy.

I wish a medical professional had warned me what was ahead emotionally, that I hadn’t had to figure this all out on my own. Discovering the advocacy organization Spinal CSF Leak Foundation, and online resources this past year have been a godsend. Sharing stories, lessons, and (most of all) hope has helped me know that I’m not alone.

*A recovering attorney and freelance writer, **Rebecca Wallick** lives in the mountains of central Idaho with her two dogs, working from home as creator/publisher/editor of *McCall Digest*, an online community magazine. When not writing or napping, she’s exploring the nearby Payette National Forest in all seasons with her canine companions. You can find her on Twitter at [@rebeccawallick](https://twitter.com/rebeccawallick).*

# Stopped in My Tracks

By Meredith Preble

**A**lmost five years ago, I was diagnosed with post-traumatic stress disorder—PTSD. In hindsight, my symptoms began years earlier, after my second diagnosis of lung cancer. I learned that cancer was a huge trigger for my PTSD, and it explained my depression and anxiety, the withdrawal and constant irritability. I was a cat who was cornered, hissing at anything that moved.

Years ago, I needed an X-ray for a possible broken rib. What I saw on the X-ray was not a broken rib, but a solid mass in one of my lungs. I remember just standing there—frozen—afraid to take my eyes off that X-ray. The radiologist came into the room and said, “This is a cancerous tumor. It is the most important thing in your life. As a matter of fact, it’s the only thing in your life. You need to see an oncologist immediately because of where your tumor is located. You have no time.”

What followed were frenzied weeks of appointments, a biopsy, scans, blood tests, breathing tests. I wanted answers, but didn’t know what questions to ask. Was I going to die? The surgeon informed me that the entire right lower lobe of my lung had to be removed. Really? How many lobes did I have? Would my lungs regenerate? Would I need to have oxygen all the time? How long would the surgery take? How long would I stay in the hospital? Would it hurt? Yes! Yes, it did. A lot!

When I awoke after the surgery, I couldn’t inhale;



when I could inhale, it was very little. Was this all the air I could breathe now?

After four days I went home with no idea of what was to come. Before the X-ray, I had been a wife, a mother, an artist. Was I a cancer patient now? As I stepped out of the hospital, I was told I should “go out and live my life.” But I didn’t want to be with anyone. I felt guilt and shame. I had been a smoker. And now, I didn’t know who I was.

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“The purpose of sharing my journey—what I want you to understand—is that PTSD is a real mental illness.”

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In the ensuing months, I tried not to think about my cancer but about living. And just like that, I made it through 10 years!

My 10th anniversary came and so did a call from my surgeon. The most recent CT scan showed two more lesions, this time in the upper left lobe. Within two weeks I was at Massachusetts General Hospital, being prepped for my second lung surgery. Seven-and-a-half hours later, I woke up. This time, because of a third tiny lesion which had penetrated the pleura, I would need a blood transfusion and chemotherapy. Also, my pulmonary artery had been nicked!

When I was discharged from the hospital I was still in shock, not really understanding what more than one lesion in my lung meant. I felt the air whisper that something was not right after the surgery. I began having debilitating migraines. Depression and anger replaced exercise. I'd curl up on my bed, emotionally cut off from the world. I was disappearing. I was petrified and yet, unable to help myself. PTSD had grabbed a hold of me.

The PTSD was robbing me of any promise, any feeling of sanity; hope oozed out of me like sap from a maple tree. In the many years of follow-up CT scans and doctors' appointments, no one responded when I told them I had PTSD. They were unequipped.

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A cancer survivor who lives with PTSD implores medical professionals to look and listen for signs that their patients are struggling with serious mental health challenges.

The purpose of sharing my journey—what I want you to understand—is that PTSD is a real mental illness. When talking to a patient, think about the implication of your words. When a patient shares something, please listen even if you aren't familiar with that information. Most importantly, please respond.

I listened to my doctors who told me to “go out and live my life.” I tried, I really did. But no one handed out instructions.

**Meredith Preble** is a volunteer mentor on Mayo Clinic Connect. She has multifocal adenocarcinoma of the lung and was diagnosed with PTSD five years ago. She chronicles her experiences on her blog, *A Journey with Lung Cancer—My 20+ Years*, and lives in Rhode Island with her husband. You can find her on Twitter at [@merpreb](https://twitter.com/merpreb).

# Don't Forget Us! Young Adults with Invisible Illness

By Sneha Dave

**M**y brain swirled as I waited on the surgery table for my colectomy, the removal of the entire large intestine. I told the anesthesiologist I was ready for him to start the sedation, knowing this is an irreversible surgery, but also knowing I would come out with a new life. I was 13. I thought to myself that for the first time in years, I could go back to school full-time. I could go on a walk in my neighborhood—I would be “normal.” What I didn’t expect was the numerous challenges in reentering society.

I was diagnosed with ulcerative colitis at age six. Ulcerative colitis is a chronic inflammatory bowel disease that is said to affect primarily the large intestine, but in truth, it affects the entire body—the joints, the mouth, other organs. In young adults, it can create emotional, professional, and social barriers. There is limited research about this, but it is not a debated fact among young patients with ulcerative colitis and other invisible chronic diseases.

Realizing the barriers that young adults with chronic illness face, I created the Health Advocacy Summit, (HAS) an advocacy event for young adults with chronic diseases. With Summits in nearly four states, this organization has become more than a support system or a fundraising organization—it is a direct tool for empowerment. HAS is not only connecting young adults with similar conditions to each other but also hosts sessions that address different aspects and needs of a chronic disease.



There is a definite need for more resources to support the community of younger patients who face chronic illness. Further, there needs to be a fundamental change in the way young adult patients are treated by the medical model. When I was diagnosed, my care was rudimentary. I would only see my pediatric gastroenterologist and the occasional specialist for other related symptoms. There was no holistic care, no addressing the psychosocial aspects of chronic disease, especially at a developmental adolescent phase.



**There is a definite need for more resources to support the community of younger patients who face chronic illness.**

Some medical facilities do have a psychologist integrated within the specialties, such as gastroenterology, which is of incredible value in early intervention therapy.

I am hopeful that other hospital systems will become focused on treating the patient as a whole, by including specialists such as psychologists within their practice.

“ There is a wide community of other young adults with invisible illnesses, and given an empowered voice and more recognition, this community can transform the healthcare system...”

Nearly 15 years after my diagnosis, I live with a J-pouch, which is my small intestine functioning as my large intestine. I'm not yet what one would classify as healthy, and I'm still seeking effective treatment while hoping for more research.

But I feel incredible! I know that there is a wide community of other young adults with invisible illnesses, and given an empowered voice and more recognition, this community can transform the healthcare system to be even more patient-centered—and more effective in not treating the patient as a number, but as a person.

**Sneha Dave** is a student at Indiana University. At age 6, she was diagnosed with ulcerative colitis, which she has successfully battled with the help of several major surgeries. She founded the [Health Advocacy Summit](#), an advocacy event to empower young adults with chronic diseases, in four states. She also created the Crohn's and Colitis Young Adults Network a nonprofit organization to connect young adults with inflammatory bowel diseases around the world. Sneha is a part of the Pfizer advisory board, an Eli Lilly consultant, and she advocates with the United Nations for the third sustainable development goal, good health, and wellbeing. Find her on Twitter at [@snehadave98](#).



# Accidental Path to a Cancer Cure

By Martin Jensen

Incontinence was a major problem for me 15 years ago. Guiding my cousins around the National Mall in Washington D.C. one day, I had to find a restroom for urinary relief several times. Later, we remembered that my father had developed incontinence from benign prostatic hypertrophy or BPH—overgrowth of the prostate—in his 70s. It seemed reasonable that I had inherited his misfortune.

A few days later, my primary care physicians confirmed I was developing an advanced case of BPH. She referred me to a urologist for consideration of how to keep prostate tissue from expanding into my bladder.

Without delay, the urologist conducted a thorough examination then initiated what became a month-long discussion. We talked about what he found, what therapy options were most likely, and, because of intensely personal concerns about sexual functions, how to engage me in making therapy decisions. In brief, giving me the last word on treatment choices.

Treatments began with saw palmetto, an ancient herbal remedy that provides relief for some men, but it wasn't enough. We switched to prescribed medication, but with inadequate relief again, we focused on surgical options to remove excess prostate tissue.

The prospect of surgery gave me pause. My father had undergone surgery with unhappy results. The tube (urethra) from his bladder



and a valve (sphincter) were damaged by the surgical procedure and he was fitted with a permanent catheter to drain his urine into an external bag. Repeated infection, where the catheter entered his lower abdomen, led to his death at age 94.

But I had learned to trust my urologist and when he told me the operation could be done without cutting anything but excess prostate tissue, I asked when I should check into the hospital. He gave me one week to change my mind and explained that he would perform a transurethral resection of the prostate (TURP). Afterward, nurses told me the tissue that had been removed was in a cluster about the size of a golf ball. I was released the next morning. The operation provided a surprise benefit: it may have saved my life. Before the prostate tissue was removed, it had concealed from view a



papilloma tumor, like a pedestal, growing on the lining of my bladder which was also removed. Microscopic examination led to a diagnosis of a “low-grade” malignant tumor.

Follow-up examination two weeks later revealed that a dozen more papilloma tumors had sprung up out of the epithelium lining the bladder. Surgery without delay was indicated, but hospitalization probably would not be required this time.

“We learned to share information fully and to develop mutual confidence, so they knew I would accept an immunotherapy treatment that promised to eliminate cancer cells from my bladder.”

The verdict this time was an outbreak of malignant “high grade” tumors. Since none of the tumors had “left the scene of the crime” (grown deeper and into the bladder lining), they were superficial epithelial growths that could be wiped out by special bacteria, known as *Bacillus Calmette-Guerin* (BCG), suspended in a solution. As described by the American Cancer Society:

“BCG (solution) is put right into the bladder through a catheter. It reaches the cancer cells and ‘turns on’ the immune system. The immune system cells . . . attack the bladder cancer cells . . . (and) come in contact with (them). This is why it’s used for intravesical therapy.”

BCG treatment is done once a week for six weeks and may be repeated for another six weeks if needed, but it wasn’t in my case. Instead, following the six BCG treatments,

my urologist visually examined my bladder lining with a cystoscope—monthly at first, then quarterly for two years, semiannually for two more years, and now annually. No additional tumors have been found since my ambulatory surgery 10 years ago.

I am grateful to be known as a cancer survivor now, 10 years after my original diagnosis in 2009. Fortunately, my urologist and his team persuaded me to be aggressive in treating my overgrown prostate. They pressed for early surgical removal of excess prostate tissue, which enabled their surprise discovery of malignant, but as yet non-invasive, bladder tumors. We learned to share information fully and to develop mutual confidence, so they knew I would accept an immunotherapy treatment that promised to eliminate cancer cells from my bladder.

I owe my good fortune to the immensely caring and determined medical professionals who could not be satisfied managing my cancer, leaving me to hope for survival. Instead, they invested in a plan to fix my bladder and announced within a few weeks that we had cured the cancer and would confirm that regularly with cystoscopy examinations over the years ahead.

**Martin Jensen** is a retired policy analyst for the U.S. Senate and the National Governors Association (NGA) which represents the chief executives of the states in relations with the federal government. As part of the Senate staff during the 1970s, he worked for the committee now known as the Health, Education, Labor, and Pensions Committee. On the NGA staff, he conducted research and provided state agencies assistance on economic and workforce development policies and programs. Since retiring in 2003, he has experience as a caregiver for two family members with disabilities, as a patient in several medical therapies, and as a volunteer Mentor with [Mayo Clinic Connect](#).

# Hope: A Strategy for Managing Chronic Disease

By Kristina Wolfe

**T**ime is one of the most priceless gifts we all have, but which can be robbed in an instant from those of us with chronic illness and disease.

From diagnosis and prognosis, to the time it takes to cope with symptoms, we are instantly required to shift our thinking to managing our time. Our priorities shift. Often, that shift is in favor of time needed to dose, adjust, rest, visit the doctor, get new labs drawn, or try a new gadget—all so that we can keep breathing.

These demands can cause an overload of information, and patients oftentimes find themselves fatigued from decision-making.

[pause]

Now, I'm back.

By the way, three hours to troubleshoot a sensor that is supposed to help me make decisions to manage my symptoms every second of every day is ridiculous! See, it's all about time.

Let's consider our roles within the space of healthcare.

## **Are you a physician?**

Have you asked yourself how you can meet patients' needs, or where they are in their journey and use that knowledge to save time and add value to their lives?



## **Do you work for a health insurance company?**

Have you asked how you could advocate for patients who need prescription drug refills that may require prior authorization or step-therapy for coverage? (Hint: Usually this means many hours on the phone and delays in delivery for patients to get the medicines...more time spent that they can't get back.)

## **Do you work in healthcare administration?**

Have you looked into mobile or technology solutions to streamline clinical access for those patients who need to see specialists frequently—to help save patients time?

“What if all of these things are working together for a greater good? What if all of the bad things that have happened are actually leading towards better potentials?”

#### **Are you a researcher who conducts clinical trials?**

Have you considered adjusting the protocols you are working on, to allow for patients to have some time back; have you asked them how you can help?

#### **Do you work for a pharmaceutical or device company that is planning to, or has commercialized a treatment?**

Have you involved patients in the clinical development process, or in launch strategy-planning to see how you might add value to their lives and align to your business strategy at the same time?

For many patients, especially young adults, the time that is lost can exacerbate anxiety and stress—factors that are considered comorbidities of many rare and chronic diseases.

#### **How do we combat all this?**

With hope—when patients focus on the possibilities of what can be accomplished despite everything, rather than focus on the issues they face.

When diseases, symptoms, management are framed as problems, our feelings of fear, doubt, and worry increase. On the other hand, when the same issues are presented as opportunities or possibilities, our energy escalates and hope becomes the primary driver.

#### **So, my challenge is for all of us to start asking the “What if?” questions.**

What if all of these things are working together for a greater good? What if all of the bad things that have happened are actually leading towards better potentials?

Disease is a misfortune, yes. It could also be an opportunity when viewed from the lens of hope. And with hope, there is faith which does for us what we often cannot do for ourselves—it gives instead of takes.

**Kristina Wolfe, MSPH**, is a hopeful storyteller, Type I Diabetes (T1D) patient, advocate and motivated young healthcare professional. She began her career in clinical research operations before moving into business development. She has successfully developed opportunities to innovate within clinical trials by raising patient voices and drive messaging with biopharma companies and investigators. Find her on Twitter at [@tunaturns](https://twitter.com/tunaturns).

# A Good Night's Sleep

By John Bishop

I was diagnosed with lymphedema last year, while undergoing treatment for pain and swelling issues with my right ankle, knee, and leg. After going over the examination and test results, the doctor asked me about my sleep quality and habits. I didn't think much about it at the time—I was more concerned about the lymphedema, and I really didn't think I had any sleep problems.

After my appointment with the Sleep Medicine department, I was sent home with an oximeter test unit, which I had to bring back the next morning. The results indicated that I would need further evaluation—an overnight sleep study.

The overnight sleep study was quite an experience! With all the wires connected to my body, one might have thought I was on life support. Yet, I was surprised when I was diagnosed with severe obstructive sleep apnea.

The good news is that obstructive sleep apnea can be treated by using a continuous positive airway pressure device or CPAP machine. My doctor explained how the CPAP works and the goals we were trying to achieve: to reduce the number of sleep events to four or less per night. When I picked up the CPAP machine and full-face mask, a sleep therapist provided more tips for using the mask and getting it adjusted. As I headed home to start my CPAP journey, I thought this was pretty much all there was to it—put the mask on, turn on the machine and go to sleep. Boy was I wrong!



This is where I have to pause and give thanks to my CPAP cyber-friends on Mayo Clinic Connect. Without them, I would have struggled even more than I did.

The first full-face mask gave me the proverbial “CPAP nose.” Within 30 days I switched to another mask which fit under and up against the bottom of the nose. But I felt like I was suffocating, and had to switch to yet another mask.

“I’m still not at the end of the CPAP journey, but the road is a lot smoother, and more importantly, I’ve learned how to be my own advocate.”

Almost 90 days after I started using the CPAP machine, I had to bring it back to Sleep Medicine so that they could download the data and verify the usage for Medicare compliance.

It seems I was complying—I used the CPAP at least four hours per night. My sleep therapist was very helpful with tips to help me overcome my CPAP nose issue. For instance, she told me that some of her patients had found a cloth cover for the full-face mask which helped keep the nose from getting chafed. She even wrote down the web address so I could look it up at home.

I'm still not at the end of my CPAP journey, but the road is a lot smoother, and more importantly, I've learned how to be my own advocate.

Being able to participate in such discussions and learning from the experience of others was extremely helpful.

I learned that many people struggle with the CPAP mask, which was also part of my struggle—I wasn't alone. This helped me start a discussion with my local sleep therapist on what types of masks others are using, and learn about the variety of masks.

I'm still not sure I have the best mask (for me), but I have one that is pretty close, and it has my numbers around five or less most nights. I'm always searching for tips on improving my CPAP usage by interacting with other patients, and as my CPAP cyber friends would say: Happy Zzzzzs!



After being discharged from the Navy, **John Bishop** worked at IBM as a Customer Engineer in Southern California and Aberdeen, SD. He transferred to IBM in Rochester, MN and worked as a technical writer until retiring in 1997. John began a second career at the Internet helpdesk with KMTelecom, and plans to retire at the end of 2019. If you ask John, "What's next?" he would most likely say, "Being able to devote more time to my new passion—[Mayo Clinic Connect](#)." Find him on Twitter at [@reala2g2](#).

I started the journey with the goal of reducing my apnea-hypopnea index (AHI) to four or less. I realized it wasn't as easy as I thought it would be. I found an online patient-support community where people were discussing how to reduce events while using a CPAP.



# If Remission is the Goal, Why Do I Still Feel Bad?

By Megan Starshak

Everyone always talks about being sick.

My life took an unexpected turn after I was diagnosed with inflammatory bowel disease (IBD). I was lost, trying to navigate the nature of this new disease, this new identity, in a new college where no one seemed to understand. So, when I found a community of patients, I finally felt like I had others fighting alongside me—I found direction.

Finding my place within the community changed my whole world. It felt as if a weight was lifted off me, not having to explain the nuances of life with a chronic illness. My community believed me, they knew my journey because they were on the same one. It was a safe and supportive space to talk about all the challenges and complexities of IBD. We talked about everything—but everything revolved around being sick.

## **Remission is the goal, isn't it?**

Short of finding an actual cure, remission is likely the goal for every patient. When I found myself spending my focus and energy on my life goals, and not disease management, I felt like I was there. We talk a lot about the sick patient experience—which is such an important topic—but it is also important to talk about remission. Yet, it is often left out of the narrative on chronic disease. When I found a treatment that worked, I unexpectedly lost myself in remission.



## **Survivor's Guilt = Remission Guilt**

I had tried every approved treatment on the market at the time, before I found one that worked. After having so many of them fail me, the first emotion that hit me was that remission is real. I spent months waiting for the other shoe to drop. I told myself not to get used to being healthy because it certainly would not last. It was a surreal and unexpected thing, to deal with negative emotions in an otherwise positive experience.

I finally did accept that my treatment was working, and that I could let go of many of the burdens of the disease. But I had some other unexpected emotions—how would I re-find my identity after living with the trauma of disease for so long? Why didn't things just go back to pre-diagnosis? Was I the only one that felt this way? Why didn't anyone talk about this?





**Remission is just a rest stop,  
and I still think constantly  
about disease decisions.**

The period of adjustment to remission is real. I learned to find my identity as someone in remission, while finding a way to connect authentically and respectfully with the same IBD community that had carried me for so long. Finally, I was happy and healthy.

That's when another unexpected emotion hit—guilt. Survivor's guilt. Remission guilt.

I went from a place where I remembered pain and struggle, to a place where disease management was frankly, easy. Now, I take one maintenance medication, I don't have a lot of side effects, and my symptoms are virtually gone. This is what I want to share with those who are still struggling. I want us to all find relief and be able to rest together. I constantly struggle with feeling like I don't deserve this and I know others do too.

Perhaps this is why we don't talk about it. Maybe it's the labyrinth and weight of unspoken guilt.

### **If You're My Physician, Know This.**

This stage shouldn't be left out of the conversation while recognizing that remission is still not a cure.

IBD doesn't stop getting treated once we're stable, and likewise, we'll have needs related to our mental health and sense of identity. As a physician, you can't look at this as the finish line. But it's okay to talk about it with patients. It's

important for physicians to stay active in our whole-person treatment because remission is a good thing—and it's better if it lasts.

This isn't the end of my story. Remission is just a rest stop, and I still think constantly about disease decisions. I always have future treatment considerations in the back of my mind and the numerous ways they might affect me. But even in the present, I'm figuring out how to facilitate the remission conversation better so everyone can understand the whole story.

**Megan Starshak** is from Milwaukee, WI. She works to empower other patients through her platform, [The Great Bowel Movement](#), so that patients can find their voice and contribute to greater awareness. Megan works full time in marketing, loves being active, discovering new restaurants, and spending time with her dog. You can find her on Twitter at [@ItsMeMegaroo](#).

# Hope for the Best, and Plan for the Worst

By Allan Butler

Life, as I knew it, was crashing down. I was sitting with my wife in the oncologist's office and had just been diagnosed with stage 4 pancreatic cancer. But, I was about to experience some of the most optimistic and hopeful words I had ever heard.

My doctor could have told me about the bleak prognosis, where only a handful of patients survive until the one-year mark. He could have prepared me for the upcoming hardships I was going to face from the harsh chemotherapy regime. Instead, he chose to highlight the positives:

1. I was a relatively young man—only 53—so I would have more stamina to fight a long-term battle.
2. The bleak survival statistics, with which I was already too familiar, are based on old data that is no longer reflective of recent advances in pancreatic cancer treatments.
3. Despite pancreatic cancer being considered an “incurable” disease, we could work together to manage it successfully through a combination of chemotherapy, radiation, surgery, and experimental treatments.

In my panicked state, and with a history of being a “glass-half-empty” kind of person, I could have been forgiven for focusing on the negative. Yet, something in his words inspired me.



Even if only a very small number of stage 4 pancreatic cancer patients, out of hundred, make it past the first year, why couldn't I be one of those lucky few?

That conversation with my doctor took place over six years ago.

Now, this isn't a storybook ending. I still have stage 4 cancer, but the past six-plus years have been fulfilling and joyful beyond belief. So, with the hope that my experience can be helpful to others, here are some important lessons I learned...

**First, recognize and accept that this is your new normal.** While you will no doubt feel a sense of loss for the activities you can no longer pursue, think creatively about the things you can do now—or might be able to do if you push yourself. As a former professional athlete, I had to give up many of the demanding sports that I

“There is immeasurable power to be gained from the energy of others.”

loved. But I was able to replace them with new activities—daily walks, crossword puzzles with my wife, sailboat rides on the waterfront—that I now enjoy just as much.

**Surround yourself with caring, supportive people.** There is immeasurable power to be gained from the energy of others. Before I became sick, I would often try to be tough. However, since my diagnosis, I've gladly accepted my wife's entreaties to take care of me. Formerly casual acquaintances have now become best friends who check in regularly to make sure I'm okay.

**Appreciate each day as a gift.** Before, I tended to take some days for granted. Now, whenever I find myself moping around, I remind myself that there are only so many days to be lived, so I better not waste them!

**Make intermediate-term goals to give your life some direction and purpose.** My kids were

just starting college when I became sick, and I desperately wanted to be there when they graduated. I was able to accomplish that.

**Then, follow up with some new goals.** Now, I'm setting my sights on my daughter's wedding, later this year.

**Think two steps ahead when it comes to your health and treatment strategy.** I always want to know what's next, whether the current treatment is successful...or if it isn't. That gives me the incentive to research upcoming clinical trials, for example, before I am in an urgent need of one. And, I seek out second, even third opinions from leading doctors.

Most importantly, I have this advice for physicians: My oncologist raised my hopes with his inspiring words. I do realize this might not be appropriate for every patient. But when given the choice between offering a patient something to live for and shifting their focus on the positive, or dashing their hopes, why not choose the more optimistic route? It made all the difference for me.

**Allan Butler** has survived four major cancer surgeries, two rounds of radiation, six clinical trials, and countless rounds of chemotherapy. He previously played professional ice hockey in France and is now retired from the National Geographic Channel where he produced award-winning documentary films.

# When the Fearful become Fearless

By Carly Flumer

The drip-drip-dripping of the sink in the radiology room echoed loudly in my brain as I waited for the pathologist. I just had a biopsy done for two spots on my neck—one suspected to be cancerous. “A nodule,” my primary care physician had previously explained at my annual physical. The radiologist had comforted me, casually saying, “I wouldn’t worry, though. There’s only a ten to fifteen percent chance.”

In just a few minutes, I would be given my fate.

In January 2017, I was diagnosed with thyroid cancer. I met my surgeon five months later. “What you have is called a papillary carcinoma,” he said. “Doesn’t cancer come from tumors?” I thought. I looked up some terms in the National Cancer Institute’s Dictionary of Cancer:

**nodule** - A growth or lump that may be malignant (cancer) or benign (not cancer)

**carcinoma** - cancer that begins in the skin or in tissues that line or cover internal organs

**tumor** - an abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Tumors may be benign (not cancer) or malignant (cancer). Also called neoplasm.

“The doctor-patient relationship has changed significantly—for the better.”



The dictionary helped, but why weren’t these words explained to me by the doctors? It sounded like all the terms were being used interchangeably, and my brain was already feeling corrupted by the diagnosis—I was struggling to comprehend my diagnosis.

My bewilderment grew as I tried to understand how the thyroid hormones, T3 and T4, worked together with thyroglobulin (a biomarker), and the pituitary gland located in the brain. I understood what hypothyroidism vs. hyperthyroidism meant, but only because I knew the symptoms of each, and would be able to tell my doctor if I was experiencing any of them.

I was told by multiple doctors that I had the “good” type of cancer, and I felt hopeless and quite stupid for asking them to repeat what they had just said, or for asking them to explain a term or biological process in a different way.

Coincidentally, I had just started my fourth month of graduate school in a program focused on health communication—one of my first classes was writing for health communicators. That’s where I learned that, as of 2003, when the U.S. Department of Education measured health literacy of various populations across the country:

- Only 53% had intermediate health literacy, or “having the skills necessary to perform moderately challenging activities.”
- 12% had proficient health literacy, or “skills necessary to perform more complex and challenging literacy activities.”
- Which means that more than 40% of the population is only able to understand the basics of their health.

It only gets worse for people living in poverty, the elderly, and racial minorities.

So how can we create health literacy equality among all populations?

The answer lies with patient advocacy and patient empowerment.

The doctor-patient relationship has changed significantly—for the better. Where once a patient relied on their doctor for information, to learn about a condition or a symptom, today, patients are finding this information online—and bringing their knowledge to appointments. They’re asking questions about their health and

treatment paths. Some are even looking for answers about things that the doctor may not have heard of...yet!

As a health care professional, are you:

- using terms that are patient-friendly or that are at grade level?
- using pictures or diagrams to simplify complex concepts?
- asking questions to make sure patients understand your instructions?
- explaining test results, documents, brochures, etc.?

Most importantly, are you taking the time to listen to the patient’s concerns, and addressing them in a clear, understandable manner?

When doctors and health care providers take time to engage with them, patients feel more empowered to take charge of their health, and to become their own advocates. When the fearful become fearless is when real change happens.

**Carly Flumer** was diagnosed with stage I papillary thyroid cancer at the age of 27. She recently received a Master’s degree in Health Communication from Boston University, and her Bachelor’s in Health Administration and Policy from George Mason University. As a result of her diagnosis, Carly looks to advocate for other cancer patients through education, research, and health literacy. Find her on Twitter at [@carlyflumer](https://twitter.com/carlyflumer).



# Empathetic Doctors Make Empowered Patients

By Chris Anselmo

**“S**o, tell me what’s been going on, Chris.”

I watched intently as my neurologist—who I had only met thirty seconds before—settled into his chair in the exam room. Upbeat and cheerful, he had a smile on his face, which is just what I needed at that moment of vulnerability. Without hesitation, I began to recount my patient story—a story I knew by heart after telling it over and over again to the countless doctors and specialists I saw in the last three years.

Staring straight ahead at the door, I told him about the curious diagnosis I received in 2004—Miyoshi Myopathy/Limb Girdle Muscular Dystrophy type 2B—an adult-onset form of muscular dystrophy. I had been in a car accident during my senior year of high school, and the subsequent bloodwork led to a “Dr. House-like” odyssey to find out why my creatine kinase levels were off the charts. I was asymptomatic at the time, played sports, and had a normal level of strength. “I wasn’t even an adult yet,” I said. “I went to college, put the diagnosis out of my mind, and didn’t think about it for five years.”

As if on autopilot, I told him how at age 21, I went for a run after work and pulled up tired; how in the next few months I kept going for runs and had to keep stopping earlier.



I told him about my increasing difficulty with climbing stairs, my first fall on the sidewalk, and how I couldn’t even muster the strength to hit the rim, the last time I shot a basketball.

Minutes passed until I caught up to the present day, May 2012. I was nearly out of breath from the continuous narration, but I was satisfied that I had properly recounted my patient journey. I glanced over at my neurologist, who nodded softly and finished writing his notes.

Then he looked up and asked, “And, how has it impacted you emotionally?” I paused—I had never been asked that at an appointment before!



Thoughts flooded into my head. What should I tell him? Should I tell him how I truly felt, or just speak generally?

Deep down, I was glad he asked. I needed to share this burden with someone other than my family—who didn't fully understand the extent of my suffering.

“ I think about that day often—it was the first time I felt like I had the support of a caring physician, who not only understood what I was going through, but who also wanted to actively help me cope with this disease.

“Well,” I started, “it’s been difficult.” As soon as I said this, I could feel long-suppressed emotions bubbling to the surface. I didn’t cry that day, but I had to speak slowly to stay composed. Five minutes later, my neurologist knew all about my hopes and dreams, my deepest fears living with the disease, and how I worried whether or not I’d ever get married or live a productive, meaningful life.

At the end, I added a final somber thought: “I feel like I am barely holding it together these days.”

I looked over to gauge his reaction; he nodded and said, “Thank you for sharing that. I can appreciate what you are going through is not easy.”

When he said those words, it felt as if a weight was lifted off my chest. For the first time I felt

like I was being treated as a person, and not just as a specimen with weakening muscles.

I think about that day often—it was the first time I felt like I had the support of a caring physician, who not only understood what I was going through, but who also wanted to actively help me cope with this disease.

The patient experience, as I’ve come to appreciate, is so much more than physical symptoms. I like to equate it to an iceberg, where physical symptoms are the 10% of the iceberg you can see above water. Patient experience—emotions, fears, dreams, frustrations—those are the other 90%, lingering beneath the surface but just as real.

The next time you see a patient, take a few minutes to ask them about their day. If they have a caregiver, ask them how they are coping, because caregivers are equally invested in the patient’s well-being, and often feel just as overwhelmed.

The questions can be simple, but when asked with tact and empathy, they can make all the difference between a discouraged patient and an empowered one—which may improve your ability to care for them, because empowerment breeds resilience and hope.

**Chris Anselmo** lives in Connecticut and works as a market intelligence manager at the [Muscular Dystrophy Association](#). Chris is the author of the blog, *Sidewalks and Stairwells*, where he writes about his experiences of living with adult-onset muscle disease. You can find him on Twitter at [@Chris\\_Anselmo](#).

# Finding Gems in the Rubble

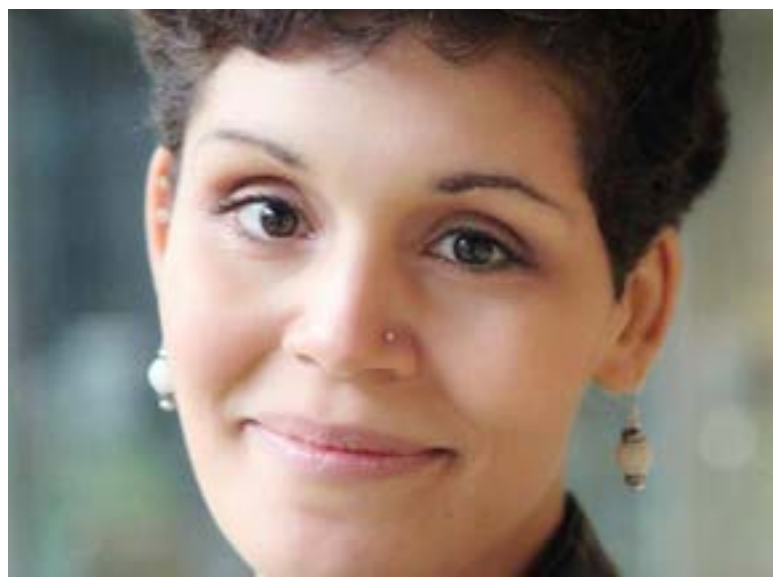
By Tiffany Kairos

It was two weeks before Christmas and just days before both our birthdays. We had been married only four months, and it would be our very first birthday and holiday celebration together. I had been thinking about my life as a wife—married life—with children, a yard, flower beds, maybe even a vegetable garden!

All of that changed on December 11, 2008. I was driving to the store to pick out birthday and Christmas presents, when I had a grand mal seizure. Lying in the emergency room, I learned that I had crashed into a tree when I had the seizure. Days later, I was diagnosed with epilepsy—I was 22 years old.

## **Understanding and accepting the unpredictable**

It can be tough to understand a condition that is unpredictable, and sometimes, uncontrollable. Medication is an excellent deterrent, but there are days when the seizures find a way around it. I've had several medication adjustments and switches in order to try and find the right combination to tame my seizures. This is known as the "honeymoon phase"—a phase when one can get away with having no seizures for a period of time. Soon enough, however, we have to go back to the drawing board of medications and combinations. I've come to accept this reality, brace myself for whatever may come, and be thankful for another day.



## **The doctor-patient relationship—a keystone of care**

A healthy and productive relationship between doctor and patient is invaluable—I was fortunate to have great medical care. I found it exceptionally refreshing to have a doctor with such a determination to help stop my seizures, who paid great attention to my questions and concerns, who went beyond our allotted appointment times to make sure that any unaddressed issues were met. Sure, he didn't always say what I wanted to hear, but he gave me honest opinions and straightforward recommendations. For me, he was more than just my doctor—he was my advocate.

### Family—growing closer together

I didn't always have the greatest relationship with my family, rarely keeping in contact with one another. Following my diagnosis, I began to notice that we were drawing closer to one another, keeping in touch with one another regularly, be it phone calls, texts, or even the occasional visit.



Today, I find myself blessed by an incredible spouse who gifted me his love, wisdom, an ear to listen, and a shoulder to cry on...and with a family who stood by our side every step along the journey. I see this as one of the biggest blessings to come out of the diagnosis.

### Being part of a community

I am one of 3.4 million people in the U.S. living with epilepsy. Living with a chronic illness can make you feel detached and isolated. Throughout the testing, the seizure streaks, the recovery periods, I would have candid conversations with friends within the epilepsy community. The community became my

extended family—reaching out during rough patches, providing me with opportunities to lend a helping hand to others. Now, when speaking with people in the epilepsy community, I drive home the point that epilepsy may be in my life, but it doesn't own my life.

### A blessing in disguise

As I continue to journey through life with epilepsy, I realize that although I never expected this condition to come into my life, I am thankful for the opportunities that I have been given—to grow as an advocate, to find a way forward to seizure freedom, and to create positive changes in the lives of others who are also on this journey.

Finding gems in the rubble. That's how I see it.

**Tiffany Kairos** is an epilepsy survivor, blogger, advocate and founder of The Epilepsy Network (TEN) Organization, an online community, devoted to providing better epilepsy awareness and education, and offering inspiration to all those affected by epilepsy. You can find her on Twitter at [@TiffanyKairos](https://twitter.com/TiffanyKairos).

# Dear Doctor: Hope and Options

By Stacy Hurt

I recently spoke to 165 first-year medical school students at the University of Pittsburgh. It was their first day in the class, “Introduction to Being a Physician,” which is dedicated to the doctor/patient relationship, and focuses on humanism in medicine. The preceptor told me that previous students, who are now medical residents, remember the course and talk about it with their patients. This was my first time speaking to medical students, and I knew it was an opportunity to leave an advocacy legacy.

I told the students about my life as a young mother of two boys, one with profound disabilities and multiple special needs, and how I juggled that with a big career...while undergoing aggressive treatment for colorectal cancer. I spoke about the two lowest points of my ongoing journey: When my older son, who was ten at the time, asked me, “Mom, are you going to die?” And, when I would sit on the couch, helpless, with a take-home pump of chemotherapy running through my veins, while my husband and elderly parents changed my younger, disabled son’s diapers, lifted him, fed him, cared for him—all the things his mother was supposed to do but couldn’t.

I talked about the utter shock and disbelief displayed by all of my doctors because I was diagnosed with cancer in 27 places in my body, despite no risk factors and no family history.

I shared my faith beliefs with the students; one of them asked, “How did you rectify those with



what happened to both you and your son?” I told her, “Life is filled with unfair circumstances. I don’t blame God. I ask Him every day for strength and wisdom to deal with all of it.”

Being a patient overshadows everything else you’ve worked so hard to achieve. It destroys any and all plans—like Kryptonite, that strips your super powers. When I went for treatment, I found it refreshing that my oncologist, physician assistant, and nurses asked me about upcoming plans, because it kept me looking ahead—talking about my plans reminded me that I was still Stacy, and still living my life.

I believe that patients ultimately want two things: hope and options. I told this class of future physicians that when delivering a devastating diagnosis, look the patient in the eye, and sincerely acknowledge that it sucks.

But also let them know that you are on their side—fight for them and with them.

It pains me when I hear that patients may have to wait for a week to learn the results of their scans. My oncologist asks me to schedule PET scans on the day that he is rounding in the hospital. After I'm done with the scans, I email the nurse, who informs my oncologist, and he literally chases down the radiologist to read the images.



Within two hours, he calls me with the results of the scan. Our lives, as cancer patients, depend on those scans! Test results should be delivered to patients in a timely manner, to minimize their anxiety.

Physicians should get to know their patient as an individual. They should ask him/her, "What is the best way I can support you?" Learn to recognize whether your patient is having a good or bad day. My oncologist knows when I'm feeling up or down—he hugs me, holds my hand, and tells me he loves me. While that may be extreme, he knows that level of closeness is what I need to achieve my best possible outcome.

I also told the students, that while many in the medical community may advise against getting attached to your patients, I'm here to tell you this: get attached. Because when you do your job correctly, they'll get attached to you—and it will make all the difference.

**Stacy Hurt, MHA, MBA**, is a 20-year healthcare executive turned patient consultant, advocate, blogger, and public speaker. She is a stage IV colorectal cancer survivor. Her work focuses on raising awareness of issues such as accessibility, hidden disabilities, and survivorship. Stacy's story has been featured worldwide on such media outlets as the Today Show, Fox News, People magazine, and Forbes magazine. She lives in Pittsburgh with her husband and two sons. She has a website, and you can find her on Twitter at [@stacy\\_hurt](https://twitter.com/stacy_hurt).



# Infusing Change

By Justin McClanahan

**W**hat if I told you the hardest thing about living with a genetic bleeding disorder, like hemophilia, isn't the joint damage, the surgeries or any of the other physical hurdles? What if I told you, what "hurts" the most is going through a lifetime worth of struggles, disappointments, obstacles, and being told no! The hardest thing is the tiresome battle of fighting a disease you cannot beat, but only try to manage.

Don't get me wrong, the repetitive internal bleeding in my joints caused by hemophilia has left its mark. Today, I live with:

- End-stage arthritis in my right knee resulting in knee replacement
- End-stage arthritis in my left ankle resulting in fusion
- End-stage arthritis in my right ankle (requires fusion)
- Beginning stages of arthritis in toes, an elbow and potentially a shoulder

Physical manifestations of diseases are often easier to diagnose and treat. The important question, that should be asked, is how the damage is affecting the patient between the ears—how can we understand what it is doing to a patient's mental, emotional health as they try to deal with an illness?



Over the years, I've had to give up many things in my life just because they've become too physically demanding. This is something that weighs heavy on my mind all the time.

Combine these losses with overheard comments from people in public, as well as in the hospital setting, and it becomes difficult to handle. Remember, not all disabilities look like the designated handicap symbol.

Take the case of when I fell and hit my head against the wall. I felt something was wrong, and was concerned I had a head bleed—which is the worst-case scenario for a hemophiliac. I went to the emergency room, and because of my diagnosis, I was seen immediately.

“So, how can medical staff treat the whole patient? It’s simple—ask questions.”

Then, I overheard staff talking, just behind the curtain. “I don’t know why he’s back here, he looks fine and there are people who have been here longer.

That’s not fair; he shouldn’t have got through so fast.” The comments bothered me—a head bleed is life-threatening! Rather than getting angry, I used this opportunity to educate the staff about hemophilia and why my concern was urgent.

So, how can medical staff treat the whole patient? It’s simple—ask questions. Get to know your patient and what defines them as a person. If their diagnosis robs them of a key attribute, help them find an alternative. Don’t focus on what a patient can no longer do, but focus on how they can find their way back or find something new to conquer.

As a child, my life revolved around sports. At age 12, my parents were instructed to stop me from playing all active sports. The risks were deemed too high, despite being treated prophylactically with factor VIII to prevent further bleeding episodes. Children are not as equipped to handle heavy decisions, especially the ones thrust upon them. I was no different, and my world was crushed. Looking back, I have little or no doubt that I struggled with depression in the time following my removal from sports.

It has been 21 years since, and although I’ve grown to understand why the decision was made, it will forever be a regret of mine—that I didn’t get to play the sports I loved with my best friends.

I’ve also learned that diseases don’t define people—rather, it is what one does in spite of their diagnosis. It took me a long time, but I found ways to adapt. Now, I exercise to stay fit, play golf, and recently started playing sled hockey with the Rochester Mustangs. I also share my health journey with medical students, hemophilia patients and their families, with the hope that my experience can help those in the hemophilia community find better ways to cope and stay healthy.

For medical staff, my goal is to help providers look beyond test results and diagnoses. Learn who your patient is, what drives them, and help them maintain their whole being. Listen, offer alternatives, and know that asking your patient to give up something they love, even if it’s in their own best interest, may only take a minute for you, but will last a lifetime for them.

**Justin McClanahan** was born with severe hemophilia in 1986. Since then, he has learned that life is about adaptability and perseverance. Currently, Justin plays sled hockey with the Rochester Mustangs. He gives an annual presentation to medical students about living with hemophilia, and gives presentations to youth, living with a bleeding disorder, on how to safely stay physically active and manage the mental effects of a genetic disease. When he’s not working in Public Affairs, Justin enjoys spending time with his wife and two sons, and stressing about Minnesota sports. He is working on building his own website to share all things hemophilia, fathering and sports, in addition to his personal takes on Twitter, @MNRube.

# Zero Harm: Why it Matters to Me

By Soojin Jun

**D**ad was in ER today,” my mother-in-law told me in her native Korean.

A week ago, while at work, Dad (a.k.a. my father-in-law) had bumped his head hard. It was only when he had to sit down because he felt a sudden coldness on his head, that he drove—after work—to my brother-in-law’s home so they could all go to the emergency room (ER). It’s a family trip whenever they need medical care because they cannot communicate in English.

While talking about his ER experience, Dad shared how the room was full and he had to wait for hours to be seen. He observed a patient walking out of the ER with a bleeding hand, followed by a nurse who herded the patient back into the ER. I thought to myself, “This is normal, Dad. Welcome to health care in America.”

Dad probably decided not to seek immediate medical care at the time of the incident because of his inability to communicate in English.

Besides being worried about the medical bill, he may have felt it was a hassle to call one of us and arrange to go to the doctor. And I couldn’t assure him that an interpreter would be available to translate his language or accurately convey the context of his communication.

I decided to pursue pharmacy after seeing tragic medical mishaps.



As a caregiver for my own father, who passed away 12 years ago, such negative experiences have made me bitter about the health care system. I decided to pursue pharmacy after seeing tragic medical mishaps—complications from multiple insulin overdoses that possibly contributed to my father’s death. It was a week before his trip to South Korea, with the hope of getting more affordable care – instead it ended up being a trip to report his death.

Once I became a pharmacist, I observed how miscommunication has led to a majority of patient safety issues—I realized I was only at the tip of the iceberg.

“By making unique issues such as interpreter services and health literacy a part of the discussion, especially for patients who face communication barriers, we can achieve the goals of zero harm in health care across the country.”

I'd often wonder whether healthcare professionals think or care about the patient population that has language and cultural barriers—everyday issues for people like my family. It was then that I decided to pursue a master's program in health communication.

My chosen path has molded me to be the voice for patients like my two Dads. Studies claim that anywhere between 40,000 to 200,000 deaths occur each year, within the United States, due to medical harm. I cannot fathom how many people like my father are out there, or how many families are affected because they don't know how to recognize medical harm, or how to communicate and report it.

How can we avoid mistakes and achieve zero harm? If you are like me, taking care of family members with communication barriers, do your best to accompany them, or consider hiring patient advocates.

Are you a bilingual health care professional? Advocate for your cultural communities to help vulnerable patients who cannot understand the complexities of our health care system.

By making unique issues such as interpreter services and health literacy a part of the discussion, especially for patients who face communication barriers, we can achieve the goals of zero harm in health care across the country.

*Wedding videographer and caregiver turned pharmacist, **Soojin Jun** is passionate about the advancement of pharmacists as providers; she has a Facebook page, "Recognize Pharmacists as Providers." Soojin Jun is committed towards patient safety and quality improvement for all, and loves bringing artistic creativity into the chaos of healthcare to solve problems. Find her on Twitter at [@jun\\_soojin](#).*

# Having the Same Goal: I Chose Life

By Lia Young

**J**anuary 2014—After three years of being treated for pneumonia, at age 35, with five children and an insignificant medical history, I learned that I had a weird-named disease—scleroderma, which had no cure. I also learned that I would need a double lung transplant.

Fast-forward to September 2016—I was admitted to a university hospital in Texas where I was monitored and treated for symptoms of interstitial lung disease for several weeks. My situation was getting worse, and I had to face my mortality. I was anxious, scared, sad...I couldn't breathe. As a nurse, I could read my vital signs on the monitor and I knew that scleroderma might just take me out.

Even so, I had tremendous faith in God, and that somehow, I would live long enough to receive a double lung transplant and live to see my children grow. I remained positive. What I didn't know was that my physicians had told my husband I needed to be placed on a ventilator and had 14 days to live. If they couldn't find a donor within those 14 days, they would pull the plug and I would die.

"Dr. Death"—a name I gave my doctor because she always delivered bad news and hardly ever spoke life into the situation—had several heart-to-heart conversations with my husband and me. At a pre-transplant meeting she told us I wouldn't be able to eat by mouth after my double lung transplant...ever.



Dr. Death went on to explain three options, none of them comforting. The first involved the words "comfort care," which I knew was code for hospice. Comfort care would also take me off the transplant list.

My second option was to be intubated, but there was a catch: they would keep me on a life-supporting ventilator for up to fourteen days or until transplant, whichever came first. Option three—just ride it out in my current state, which would likely conclude in a code blue situation and the end of my life.

We chose to save my life. I told Dr. Death that I only wanted intubation as a last resort to extend my life. She placed a thin hand on my shoulder, in an almost robotic-like manner, and said, "I know you're religious, but it's time to start dealing with reality."



If only I had the breath and energy to gasp and cuss, I would have. But I didn't, so I just smiled and thought, how dare she!

“As a nurse, I could read my vital signs on the monitor and I knew that scleroderma might just take me out.

My condition continued to decline, and I was placed on a ventilator. The doctors approached my husband about pulling the plug, but he would not let me die so easily. He went online, researched “high risk double lung transplants in the US” and found a medical center in Maryland where I might have seen my life extended long enough to receive a transplant. Two days later, miraculously, I received my double lung transplant. The doctor who placed my right lung told me that the transplant was very intricate—my family and I are forever grateful for their efforts.



When I returned to Texas, six months after my transplant, I walked into the transplant office, wanting to thank those physicians and coordinators who were supportive, and let them

know that I had made it. I have not seen Dr. Death since my hospitalization.

I've visited there several times for checkups, and have attended their staff meetings, performed interviews, met with current patients, and spoken at Donate Life events to share my experience—and to say thank you.

As a healthcare professional myself, I understand the obligation to inform patients of their prognosis. But I felt disrespected, as if my home team did not have the same goal that I did, which was saving my life. Physicians should respect the wishes of the patient and present the difficult information or prognoses without offending their patient's spirituality or positivity.

**Lia Young**, a native of Palestine, Texas, is assistant director of nursing at a pediatric hospital in Dallas. She attended Texas Woman's University and obtained her Bachelor of Science in Nursing. She is the author of the book, *No Matter What...I Still Win*, (available on Amazon), which chronicles her inspiring scleroderma and lung transplant story. She enjoys being a mentor and resource for individuals undergoing lung transplantation and other medical crises. She encourages those seeking more information on scleroderma to visit the [Scleroderma Foundation](#).

# Knowledge = Power = Action

By Taylor Kane

In 2001, at the age of three, my primary focus in life was watching Powerpuff Girls—and keeping my one-year old brother from drooling on my collection of stuffed animals. Not surprisingly, I didn't notice when my dad started acting strange. Even my mom was unconcerned at first—his personality changes seemed trivial enough.

Usually an early riser, my dad began sleeping in. He stopped joking around as much, and would leave his desk cluttered with unopened mail and stacks of papers. My mom knew something was wrong when he told her he got lost driving to work, and that he couldn't figure out how to tie his Oxfords.

## **Terrifying news**

The doctor referred him for diagnostic testing, and my parents received terrifying news with the results of the MRI. The white matter in my dad's brain was deteriorating as the result of a rare, genetic disease—adrenoleukodystrophy (ALD)—and there was no cure. Our lives were forever changed.

Shortly after, my parents met with a neurologist and were dealt another devastating blow—due to the x-linked recessive inheritance pattern of ALD, I was a carrier of the disease and had a 50% chance of passing it on to my children in the future.

Over the next two years, my dad lost his ability



to walk, talk, swallow, and understand the world around him. A smart, outgoing, fun-loving father became a man who was completely bedridden, fed through a tube—who no longer knew who I was. In December 2003, a few days before my fifth Christmas, my dad passed away.

## **What it meant to be a carrier**

I can hardly believe that it's been almost 16 years since then, and I'm set to graduate from college. While growing up, I learned about my carrier status of ALD in small doses, with my mom explaining and re-explaining it to me over the years, with increasing detail. After my 13th birthday, we met with one of my dad's former neurologist and genetic counselor, who explained what it meant to be a carrier and discussed my options for having healthy children one day.

Around the same time, we learned that my carrier status could affect me in other ways—that I could also develop physical symptoms of the disease.

“Referral to specialists, genetic counselors and patient advocacy groups is often warranted.”

We were previously told that female carriers of x-linked recessive diseases were completely asymptomatic, but several studies of ALD carriers had recently revealed that while the disease was only very rarely fatal in females, most carriers did eventually develop symptoms of the disease—difficulty walking and balancing, pain and numbness of the lower extremities, and bladder and bowel dysfunction.

### **Determined to dig deep and find my inner strength**

Learning all this at a young age did not frighten me nor dampen my enthusiasm for the future. On the contrary, it made me determined to dig deep and find my inner strength—it empowered me to take action.

I became involved in advocating for women and girls who carry ALD and other x-linked diseases and began speaking at medical conferences all over the US and around the world. I repeatedly lobbied federal and state representatives to support legislation that would benefit carriers and others affected by rare disease.

A few years ago, I founded a nonprofit organization, Remember The Girls, that works to improve the lives of carriers of x-linked recessive disorders. I’m glad that my mom told me about my carrier status at a young age because it empowered me not only to educate myself but to advocate for fellow carriers

who often feel isolated and overlooked by the medical profession.

### **Females are not “just” carriers**

It is important for doctors to recognize that while traditionally regarded as “male-only” diseases, x-linked recessive disorders can and do affect females. Whether it’s ALD, Hemophilia, Duchenne Muscular Dystrophy, Kennedy’s Disease, Chronic Granulomatous Disease, or another disease with a similar pattern of inheritance, females are not “just” carriers.

Time and again, these women experience dismissal of their physical complaints as being imaginary or related to another medical ailment because “carriers don’t get symptoms.” Such misinformation is disheartening, and x-linked women must be heard, and their symptoms taken seriously. Referral to specialists, genetic counselors and patient advocacy groups is often warranted, and it is critical that women be included in clinical trials.

As for me, I’m well aware of the symptoms I may develop and the challenges I will face as I grow older. But then again, I’m a firm believer that knowledge is power.

**Taylor Kane** is founder and president of the non-profit organization, *Remember the Girls*, an international support and advocacy group which unites, educates and empowers female carriers of rare genetic disorders—a group which is underrepresented and often overlooked by the medical profession. She published a memoir, *Rare Like Us: From Losing My Dad to Finding Myself in a Family Plagued by Genetic Disease*. Taylor is a senior at The George Washington University, where she is pursuing a degree in Political Communication and a minor in Women’s Studies. Find her on Twitter at [@taylorkane23](https://twitter.com/taylorkane23).

# An Invisible Illness

By Ingegerd Enscoe

## First Encounter

I was 48 years old when I first encountered serious illness—I was diagnosed with breast cancer. It came as surprise since no one in my family had breast cancer. I needed a mastectomy and underwent six months of chemotherapy—the toughest 6 months in my life! Consequently, I had a severe intestinal reaction which, as I discovered later on, would turn out to be the cause of my gastrointestinal autoimmune disease.

## Facing Changes in the Dark

In 2005, after having retired early, we left New York for the sunny retirement paradise, Hilton Head Island in South Carolina. All was fine until late 2008, when I developed severe colitis that lasted for weeks. A biopsy showed autoimmune colitis. Although I was treated successfully, my symptoms returned, with constant abdominal discomfort and intense abdominal pain after eating. The local gastroenterologist seemed unable to deal with my continued distress, but I knew I couldn't go on living like this. My lifestyle changed—I had to give up activities, tennis, travel, social interactions. It was difficult to explain what was going on, to family and friends, when I didn't really know myself!

## Still No Answer

In 2011, I decided to go to Mayo Clinic, and was at once impressed by the planning and efficiency of each visit. I made several follow-up visits over the next 3 to 4 years; some biopsies



indicated chronic intestinal inflammation, but no definite diagnosis was made. The only thing I knew was that prednisone, in different forms, made me feel temporarily normal—a brief, wonderful feeling.

## A Clue

By the end of 2014, I was feeling more miserable than ever with the increasing and intense pain I experienced after meals. My local internist referred me to a hospital in Charleston, SC, for a second opinion. Almost immediately, the gastroenterologist found a significant clue, and a CT angiogram confirmed the findings.

The celiac artery, which supplies blood to large parts of the intestines and abdominal organs, is one of the most important arteries in the abdomen.



“Physically, I am resilient. But living with discomfort 24/7 for so many years has taken its toll, mentally—I call it chronic acute stress

An abnormal abdominal-pelvic Doppler ultrasound indicated a blockage in the celiac artery, and there was pressure on the artery by a ligament – the median arcuate ligament. The reduced blood flow and increasing pressure was the cause of my intense abdominal pain.

### Satisfaction ‘not’ Guaranteed

I met with the surgeon, who explained that Median Arcuate Ligament Syndrome (MALS) is very rare. Surgery could release the ligament’s pressure on the celiac artery, but there was no guarantee of success.

I had the surgery in 2015 and my pain disappeared for a while, only to return within a few months. The artery was still deformed; this time a stent was placed. Although the stent is working well, I still have problems with bloating, discomfort and severe fatigue. In follow-up visits at Mayo Clinic, my doctors discussed treatment plans and I decided to try immunosuppressive therapy. I discontinued the medication after a few months, since I was very susceptible to infections, but the resulting remission was very encouraging.

### Mental Burdens

Physically, I am resilient. But living with discomfort 24/7 for so many years has taken its toll, mentally—I call it chronic acute stress. I was mentally tired, and the degree of brain fog frightened me. I have always loved reading, but stopped because I had to focus too much.

I tried returning to the tennis courts and just practiced hitting balls – it felt as if I had never played tennis before! I was scared, and felt alone – another consequence of moving to a new town and being absent from social activities for several years.

### A New Normal

Practicing medicine today is complicated. Recent research has shown that people like me, who have severe intestinal damage due to chemotherapy, could develop an atypical intestinal autoimmune disease like MALS. My advice to physicians is to never give up on your patient, especially with female patients. It is not “in our heads”, or hormonal or common for “women of a certain age”. Take the time to talk to the patient, go over their history, recommend tests so that nothing is overlooked or missed.

Although It has taken me a long time to get back to normal—a new normal—I am grateful for the care I received from so many excellent and compassionate physicians.

**Ingegerd Enscoe** is a retired pediatrician. She was born in Sweden and attended medical school in Germany where she met her husband, Stuart—an American in the military. After getting married, they moved to Long Island, NY, where she eventually obtained her MD degree and went on to join a large medical practice. Being affiliated with a university hospital, she taught medical students and received the academic title of “Clinical Assistant Professor in Pediatrics” at Cornell University. They have 3 children—two have joined their parents in Hilton Head, SC, where Ingegerd and Stuart retired in 2005. You can often find her on the tennis courts or walking her dogs.



# The Importance of Hearing What Is Not Said by Patients

By Monica St Claire

It's easy in life to get hung up on what someone has said. And for good reason: there is so much obvious and embedded meaning comprehend in the what people say and even in how they say it. We are also often anticipating and looking for specific information within the communication of others, hoping to inform our own set of knowledge and advance our own goals.

This concept is never more important than when we are considering what patients and caregivers share--and what they don't share--about their health and their care.

The study of sociolinguistics, especially its subfield of discourse analysis, teaches that everything in human communication is meaningful and tells us something--something about the communicator, something about their perceived relationship to the recipient of the communication, and to the content being communicated.

But the pillars of sociolinguistic and discourse analysis do not stop at what is said; in principle, sociolinguists believe that in order to truly appreciate what someone has communicated, you have to also consider what they did not say, or, similarly, what they could have said but did not. This helps provide perspective and nuance to each statement and helps with the interpretation of others' communication, whether it is a deliberately crafted message, like an important work email, or a free-flowing, natural recounting of a personal story to friends.



And then there's the appreciation of narratives. Think about the last story you told. Think about what details you chose to include and exclude, and why. And how the "picture" would be different if those details changed.

There are countless instances in which the increased appreciation, understanding, and scrutiny of language can affect the countless interactions in health care. But on the topic of considering and recognizing the value in what patients and caregivers share and do not share, I'd like you to consider a patient or caregiver response to a direct and important question. If possible, imagine or recall a response that took the form of a narrative and especially one that either didn't adequately answer your question or provided too much seemingly unnecessary information.

Why is that? They heard your question.

In this case, you may be fully aware of what wasn't said, since you feel your question was left partially or fully unanswered. But to the patient, relative to their reality, they have or have attempted to share the most salient and important information. And this presents a number of important possibilities:

- they don't fully understand your question. Thus, they are unable to answer it according to your expectations.
- the question is not representative of their lexical, practical, or conceptual health reality and therefore, to them, there is no "direct" answer, and/or.
- they are trying to communicate the topics and information that is most important and relevant to them, regardless of the question asked.

In these instances, comparing what they are actively telling you with what they are not telling you can help you get the information you are seeking, while also helping to detect areas of potential misunderstandings. It will also help you evaluate and possibly optimize your line of patient or caregiver-focused questioning, as well as give you an opportunity to step into their world, via their narrative and what they wanted to share with you.

“There are countless instances in which the increased appreciation, understanding, and scrutiny of language can affect the countless interactions in health care.

Another key example of the importance of what isn't being said by patients comes from social

media. In my professional experience, health care providers, researchers, and other industry professionals assume that patients talk about certain topics, certain side effects, certain risks in their online communication, especially among each other on support forums. Often, these assumptions are based on attributing the topics that are personally relevant to those seeking to gain insight into patients and caregivers. When professional communication experts demonstrate that the topics and information that patients and caregivers choose to discuss and share online do not match the previously held expectations and assumptions of those awaiting the results of the research, their reactions are often a mix of surprise and frustration.

Simply put, patients and caregivers share online what is most important to them. The unstructured authentic, unprompted (in the conventional research sense) communication in healthcare social media reveals topics that are most relevant, questions, and emotions they have at specific points in their journeys, and the words they use to describe what they are experiencing.

The absence of a particular topic is also telling. Typically, they aren't talking about something because they may not be aware of it. Or, it may not be important to them. Maybe it may not be as important as the things they are choosing to talk about.

Recognizing and appreciating both the information patients share and the information they do not share provides a doubly-as-insightful perspective on the patient experience, patient outcomes, and the information that patients hold.

*A sociolinguist with a focus on healthcare communication and research, **Monica St Claire** was the head of Inspire's Insights Product line.*

# Stories: The Journey to Utopia

By Victor M. Montori, MD

**G**aleano, the Uruguayan writer, tells the story of an Argentinian filmmaker's response to a student who asks about the purpose of utopias. Utopias are like the horizon, he says, in that no matter how many steps we take, we can never reach it. He adds, "What, then, is the purpose of utopia? It is for that, for walking." I would add that the footsteps that mark the distance covered in our journey are stories.

In October 2017, I published *Why We Revolt*. As its subtitle indicates, this book, makes the case that we need to turn away from industrial healthcare toward careful and kind patient care for everyone, but I could not have made that case without stories.

People often demand, "Show me the data!" as if these data will depict the true situation. I have yet to see data depict human suffering—the suffering that results from industrial healthcare, for example—with the same vividness and clarity, with the same truth, as reflected in stories.

In this sense, stories are more likely to capture the human experience, the human yearning for careful and kind care for all.

At Patient Revolution –a nonprofit Mayo Clinic-spinoff—we've begun to assemble a Story Library –stories that patients and clinicians have sent in response to *Why We Revolt*, using the language proposed in the book.



These are stories of incidental cruelty and accidental care, stories of efficiency without efficacy, of greed pricing people out of the care they need.

These are stories of patients that appear as nothing more than a blur to their clinicians, of the burden of care that an industrial healthcare system imposes upon the lives of caregivers, by delegating completion of more medical errands, but there are also stories of elegant care which is neither wasteful nor hasty; of clinicians appreciating patients and their situations in high definition, attending to their biology and their biography.

There are stories of people working on behalf of others, of empathic connections and solidarity, and of relationships of care and love.

Clinicians can access the dysfunctions of our organs and the many ways our bodies fail, through sophisticated laboratory tests that pry open the secrets of genes and microbes that lie in our gut. But, when patients and clinicians come together to make important decisions, stories help them see the patient in all their problematic human dimensions.

“Stories give events a sequence, a tempo, and can help clinicians arrive at a diagnosis.”

To understand the whole dimension of the problem, they must go beyond the biological—consider where each person comes from, what they value, what their lives are about, and what matters to them. This knowledge is only accessed through conversation—for within these conversations are the stories that help co-create plans of care.



Stories give events a sequence, a tempo, and can help clinicians arrive at a diagnosis. It is through stories that they gain an appreciation of the life and loves their treatments are about to disrupt. It is through stories that clinicians

can learn how well their care plans have weaved through the drama of life—so that the end result is the co-creation of a program of care that best fits into patients’ lives.

Industrial healthcare, with its distracting computers and its efficiency metrics that accelerate visits, leaves little time for conversation. It shouldn’t come as a surprise then, if clinicians are increasingly burned out because they see little meaning in their work; or if patients celebrate, like they’ve won the lottery, when they find a clinician who listens to their stories. With little opportunity for conversation, without the time to listen, we may perhaps arrive to the correct response for a patient’s situation, but only by accident.

Stories are essential, as part of conversations if we want to form relationships of careful and kind care—in which we try and fail, and try again. And it is through the stories we choose to share, that we will create a movement. And as we walk together toward a better horizon, our stories of care will tell how far we have come.

**Victor M. Montori, M.D.**, is Professor of Medicine at [Mayo Clinic](#). He is a practicing endocrinologist, researcher, and author, and is a recognized expert in evidence-based medicine and shared decision-making. Dr. Montori developed the concept of minimally disruptive medicine and works to advance person-centered care for patients with diabetes and other chronic conditions. He is the author of *Why We Revolt—a Patient Revolution for Careful and Kind Care*. Find him on Twitter at [@vmontori](#).



# From Empowering to Empowered

By Lee Aase

**M**y story begins at a time when there was little information about celiac disease, and when going gluten-free was a trend or a lifestyle choice.

As leader of the Mayo Clinic media relations team 15 years ago, I became aware of how patients were increasingly using blogs, discussion boards, and other social networking tools to share information, find support, and learn more about diseases and health conditions. I noticed how social media were rapidly developing as the new “places” for patients to share word-of-mouth recommendations—an important information source for many patients.

Simply put, the technology and social media that people had used for entertainment, social networking, chat groups, were now being used as resources to get health information and support.

That’s why Mayo Clinic decided to make an investment in social media, early on. Starting with Facebook in 2007, and moving quickly to YouTube, Twitter, and various blogs, Mayo Clinic was one of the first academic medical centers to establish “a thriving online patient community,” Mayo Clinic Connect.

It just made sense: if patients were using these platforms to discuss their health, then Mayo Clinic should share its expertise and empower patients with the knowledge to make good



health care decisions. As we described it in 2010 when we established what has become the Mayo Clinic Social Media Network:

“Mayo Clinic believes individuals have the right and responsibility to advocate for their own health, and that it is our responsibility to help them use social media tools to get the best information, connect with providers and with each other, and inspire healthy choices.”

So I was a believer in the power and potential of social media in health care.

## **Then one day it got personal.**

I had been donating blood regularly, and noticed that my hemoglobin was steadily declining, until finally it reached a level at which I was no



longer eligible to donate blood. My primary care physician identified the underlying cause: celiac disease.

The diagnosis meant that any presence of gluten (a sticky protein found in wheat, barley and rye) triggers an immune response in my body, which damages the villi—finger-like projections lining the small intestine. With normal villi the small intestine’s absorptive surface area is about the size of a tennis court; celiac disease reduces it to something more like a ping-pong table! I had become anemic because my body wasn’t absorbing iron.

The good news about celiac disease is that for many patients eliminating all gluten from the diet can reverse intestinal damage. The bad news? At the time of my diagnosis, there wasn’t as much awareness of this disease, and very few restaurants served gluten-free meals.

My gastroenterologist, Joseph Murray, M.D., at Mayo Clinic is one of the world’s leading celiac disease specialists. Affable and plainspoken, he makes sure his patients understand “everything you always wanted to know about gluten but didn’t know to ask,” and he can explain all of the science behind celiac disease. See this helpful explanatory video I shot with him.

But what Dr. Murray couldn’t tell me was how to cope with celiac disease in my daily life, such as where to find a gluten-free restaurant when I was traveling. For that, I had to connect with fellow patients.

In those early years with celiac disease, I regularly used Twitter to crowdsource recommendations for gluten-free restaurants. I read blogs by other celiac disease patients; my wife also relied on these blogs and discussions as she was learning to cook gluten-free meals.

Thankfully, many restaurants serve gluten-free cuisine today, and you can find gluten-free products in grocery stores all over the country. With national chain eateries, food markets, farm-to-table and upscale restaurants becoming more gluten-aware, living with celiac disease has become easier—and much more manageable.

Yet, despite all the progress, we inevitably turn to the “experts by experience”—our peers, who live with the disease. Our online presence has evolved so much, that when we find people who are coping with similar illnesses, we connect with them. We reach out to fellow patients for support and insight—not only because their story sounds familiar, but their shared experiences help make sense of our health struggles.

It is with mixed emotions that we bring the Experts by Experience series to a close. But this is not the end of your stories. Your voice matters, and when you share your stories—the trials, the experiences, what you’ve learned on your journey to better health—you offer others hope and strength in knowing that they are not alone.

I am honored to write the final column—as a patient—for Experts by Experience. The series has been a wonderful collaboration between Inspire and Mayo Clinic Connect—social networks that recognize and value the power and potential of patient and caregiver stories to connect, teach, and improve health care.

**Lee Aase** leads Mayo Clinic’s Social & Digital Innovation team, which manages Mayo Clinic’s presence on general purpose social networks like Facebook, YouTube and Twitter as well as its owned blog and community platform. Key sites include Mayo Clinic Connect, Mayo Clinic News Network, and Sharing Mayo Clinic, a patient stories blog. He also is director of the [Mayo Clinic Social Media Network](#). Find him on Twitter at [@LeeAase](#).