

EXPERTSTM 2018 BY EXPERIENCE

Patient stories that teach



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Introduction

“Tell me a fact and I’ll learn. Tell me a truth and I’ll believe. But tell me a story and it will live in my heart forever.”
– North American Indian proverb

For health care to be successful, medical professionals need to pay attention to the human experience—a patient’s journey, a caregiver’s perspective, a communicator’s knowledge.

That’s why [Inspire](#) was founded in 2005, and now has more than 1.5 million members in its social network; and why Mayo created its thriving [Mayo Clinic Connect](#) online patient community in 2011—to provide welcoming, safe places for patients and caregivers where they can share experiences, find support, and they know, “Managing a health condition is a journey, but you don’t have to do it alone.”

Together, we’re proud to feature patient stories published in the [Experts by Experience](#) series on the Mayo Clinic Social Media Network in 2018. It is our hope that these stories will become a powerful tool for patients, to give voice to their experiences, and a resource for healthcare providers, to turn knowledge into action.

Many thanks to John Novack, Communications Director for Inspire, as well as Colleen Young, Mayo Clinic Connect Community Director, and Series Editor Kanaaz Pereira, Mayo Clinic, for their work in bringing this collection together. Our deepest gratitude to all those who contributed to this compilation, for your insights, for your honesty, and for trusting us enough to share your story—sometimes raw, sometimes uncomfortable to read, but always authentic and insightful.

We describe this compilation as “stories that teach” because patients and caregivers are educators in so many ways—they teach us to meaningfully explore the potential of healing medicine, grounded in personal experience.

Across health care worldwide, may we continue to learn from them.



Lee Aase, Director, Mayo Clinic Social Media Network

Brian Loew, Founder/CEO, Inspire



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 1.5 million patients and caregivers, representing more than 3,600 health conditions.

Experts by Experience 2018: Patient stories that teach editorial team: Lee Aase, Gregory Kolen, John Novack, Kanaaz Pereira, Eric Taylor, Melissa Tsai, Colleen Young

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Kindness at the Margins for Caregivers

By Renata Louwers

With age, most of us realize the value of a solid night's sleep, good nutrition, and exercise. We come to understand that this self-care greatly impacts how we feel, function, and perceive events around us.

This is exponentially true for family caregivers of a person facing a terminal illness. Life as a caregiver to a spouse with stage IV cancer can feel like living a sleep-deprived, fast-food, no-exercise day, every day for months and sometimes years.

It is in this context that kindness at the margins—especially from doctors and nurses—can make an even greater difference than it normally would.

If you are a healthcare professional, please assume that caregivers to the seriously ill are sleep deprived, eating on the run, and unable to exercise. In addition, they are sad, deeply sad, and scared. They see life through a dark lens with a burden on their shoulders. What you do—whether you are extra kind or terse—is magnified from their perspective. Your actions, your attitude, your willingness to make their day a little easier—even if that adds a little hassle to yours—can impact their well-being.



When my first husband, Ahmad Khoshroo, had stage IV bladder cancer, we spent many days in waiting rooms, infusion labs, and in the emergency room—eleven months of exhausting interaction with the healthcare system. Two separate experiences in emergency rooms reminded me of the impact hospital employees can have.

In one instance, we arrived by ambulance and there were no beds available. My husband was on a stretcher in a hallway, and there was no place for me to sit. I was fatigued, but no one offered me help. Instead of empathy, I was scolded when I sat against the wall in the hallway.

Conversely, in another emergency room visit, we arrived late at night with the worry that he had developed a blood clot in his leg. A nurse could immediately see how tired I was. He brought me a pillow and said, "There's a waiting room down the hall that's empty this late. You can take a nap there and I'll come get you when the doctor comes to talk to your husband." It was as if I'd been given a free upgrade to



first class. It was a small thing that cost the hospital nothing, but I couldn't have felt more appreciative. I appreciated the opportunity to rest and that someone recognized what I needed and offered it to me. I didn't have to ask or demand; I didn't have to do anything.

I understand that in an emergency room the top priority is to handle emergencies, not to comfort caregivers.

“ I appreciated the opportunity to rest and that someone recognized what I needed and offered it to me.

But it takes discreet actions like kindness, helpfulness, empathy—things within the control of every person—to scale up the humanity of care.

And scaling up, even slightly, can have a big positive impact on caregivers.

Renata K. Louwers, patient advocate and writer, is the editor and co-founder, with her husband, Tim Louwers, of the literary journal and nonprofit organization, [Months To Years](#). It explores death, dying, and mortality through creative nonfiction, poetry, and art. She was the caregiver to her first husband, Ahmad Khoshroo, during his 11-month treatment for stage IV bladder cancer. Find her on Twitter at [@RenataLouwers](#) and [@MonthsToYears](#).

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#ExpertsbyExperience offers a window into the human heart of medicine.
[@JBBC](#)



Multiple Sclerosis, Illusions, and “Working Understandings”

By Gil Greenman

Living with a chronic illness often means confronting your denial. I lived for eight years with multiple sclerosis (MS), thinking that my brain was beyond having new lesions. This was because I was taking a powerful drug called Tysabri. All my MRIs showed no new lesions. However, my disease did progress, and I moved from walking unaided to walking with a cane.

Doctors took me off Tysabri, because they were not sure what it would do to me after eight years of taking it. I dealt with the worry about going on a new oral drug by telling myself that my current disease course was “secondary progressive” MS – what I believed was a disease phase where the body may progress, but new lesions did not form.

This denial was punctured by an MRI six months after I stopped taking Tysabri. There they were, looking at me like two owl eyes on my frontal lobe, the place where executive function lives. New lesions.

It was terrifying! For so long I trudged through complicated chapters in my life thinking I knew what the distant shores of new life would likely hold.



The next lesions could catapult me into a totally different place. Pain, paralysis, optic neuritis all seemed possible.

My doctor's immediate response was to put me back on Tysabri, but my blood was not ready to receive it without an unreasonable risk of intentionally fatal infection. Today, a couple of years from the onset of this crisis, I am on the latest drug, but am still having new lesions. Just like the oral medication was an illusion, my current medication may be an illusion as well. People like me often live in a world of denial and illusions. We sometimes call them “working understandings.” They are based on some facts, some experience, and more often hope. Some serve us for years and drive many good decisions.

What is not an illusion is that everyone is unique—everyone, and certainly the presentation of the mystery of MS in each person living with MS is unique. We just don't know for sure what will help. All we have are studies, (with good or poor outcomes), and our experiences. And uncertainty—we try to get the best information and counsel we can, but ultimately, we must make a decision about what to do, every day. And, when we take the time to explain the journey to family, friends, and caregivers, we often receive enormous support. I know I have.

So now I must become bigger, like a wave in the vast ocean. I must let the tide take over, and if a good option arises again, hurl myself upon it. Until then, you will find me trying to float on the

“ So now I must become bigger, like a wave in the vast ocean. I must let the tide take over, and if a good option arises again, hurl myself upon it.

water of faith—faith that I am enough, worthy of love and belonging, and that the universe unfolds as intended. I struggled my whole life to find this faith. Looks like it's time to cast off now, to trust the supporting waves beneath me, replace denial with acceptance, and live the next chapter of this life.

Gil Greenman is the author of the blog, *A Fortunate Man with MS*. He is a trustee of the Pacific Northwest Chapter of the National Multiple Sclerosis Society. Find him on Twitter at [@fortunatemanwms](https://twitter.com/fortunatemanwms).

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Patient stories are teachable moments, providing rich insights into the embodied experience of illness. Listen for what lies “between the lines.”
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Grieving the Loss of Your Physician

By Kari Ulrich

Navigating an unexpected loss of a medical confidante

Reflecting on my health, one of the most challenging experiences I faced as a patient was losing my primary care provider. Physical and mental health are continuously challenged when you are diagnosed with a chronic disease. For me, being diagnosed with fibromuscular dysplasia (FMD) and Ehlers-Danlos Syndrome was complicated with another diagnosis—median arcuate ligament syndrome (MALS). Not only is MALS a diagnosis of last resort, but it is also controversial as many health care providers do not believe in its existence—it took two decades to figure out what was causing my symptoms! My MALS was validated upon diagnosis of FMD, when they discovered that the celiac artery—the artery that supplies the vital organs and gut—was significantly blocked due to a ligament cutting off blood supply to my abdomen. The treatment for this condition is surgery.

It took me three years to gather the courage to consult a vascular surgeon. My reluctance was met with the fact that I have fragile arteries, and I feared the surgery would cause my small brain aneurysms to rupture. “What ifs” plagued my mind, but realizing that my health was deteriorating, and malnutrition was setting in, I met with my vascular surgeon. I explained my fears, asked him questions which he diligently answered, and we scheduled my surgery.



I arranged the pre-op appointment with my primary care physician who was a consulting doctor on my team of neurologists, vascular doctors, nephrologists, cardiologists, gastroenterologists, and genetics specialists. Due to changes in the medical team she became my primary care provider, and has seen me through my rare disease diagnosis, through research at the National Institute of Health, and now, as I faced open vascular surgery. Our physician-patient relationship had been established for about a decade at that point. She had trust in me as a patient, as much as I had confidence in her as my physician.

The surgery was a success, and recovery took about a year. However, my symptoms returned, and three years later I faced another surgery, this time exploratory in nature—my bypass graft was revised and scar tissue was removed. I met each setback, knowing my primary care doctor was by my side—we celebrated my successes, and we cried together when life was too much to bear.



My most difficult experience was saying goodbye to her several years ago. Her life was changing, and for reasons beyond her control, patient care would no longer be possible.

How does one grieve the loss of a physician, your health care cheerleader, your confidante? Health care providers argue that you cannot become involved in patients' lives, and that patients must understand boundaries in the provider-patient relationship. Nevertheless, we do form relationships, and it is normal to grieve the loss of any relationship, especially when you have shared decades of experiences. I went through the same stages of grief that I would with the death of a family member or a close friend.

Depression and despair can set in as you realize a situation cannot change. For a patient, fear and the "what ifs" set in—what if the doctor does not believe in my pain; what if his or her style of care is not patient-focused; what if I lose control over the quality of life I have worked so hard to achieve? Eventually, acceptance of loss does happen, and the experience of knowing what makes a good provider helps in establishing your next provider. "What if" statements are replaced with "I will" statements:

- I will now expect my doctor to treat me as a team member who can make educated decisions along with their expert guidance.
- I will communicate my expectations to my next provider, and ask how we can achieve goals together.



We celebrated my successes, and we cried together when life was too much to bear.

- I will respect my provider's thoughts and appreciate his/her wisdom, as without it I cannot make informed choices about my care.
- I will therefore, acknowledge differences, and be patient in developing a patient-centered partnership.

As with most things in life, we must give them time to grow and develop. I will always hold what my primary care doctor gave me, close to my heart—her gift of medicine and healing—the most cherished gift I have received.

Kari Ulrich is a volunteer mentor for [Mayo Clinic Connect](#), in addition to serving on the Board of Trustees for [The Naeve Health Care Foundation](#). She is a part-time student working towards her BSN. Before her diagnosis, she worked as a RN and has both pediatric and adult emergency room experience. For her 50th birthday, she started taking western pleasure horseback riding lessons with the goal of competing in a show someday. Find her on twitter at [@FMDGirl](#).

After Surviving a Brain Tumor, I Made Time My Friend

By Claire Snyman

When the sledgehammer of illness hits, it can be hard to adjust. Whether it is an acute or chronic illness, trying to make sense of it and make changes in our lives can be tough. May 18, 2010, changed my life and my family's, forever. After acute onset of vertigo and migraines, I was diagnosed with a rare non-malignant brain tumor. Two years later the tumor doubled in size. I had brain surgery to remove it and save my life.

I was told to expect at least a year before I'd recover, but nothing prepared me for the crippling fatigue that would infiltrate every fiber of my brain and body. I was accustomed to being on top of my game—every day. Life was about to teach me a big lesson, but I was not yet ready to listen or learn.

My acute recovery consisted of days of endless sleeping as my brain recovered from its unexpected trauma. I struggled with heavy fatigue, short-term memory loss, and my body felt like it had been through a minefield.

Every time I tried to do something—familiar things—my body and brain rebelled. I spent days in bed recovering, even from doing the small things I had taken for granted before. The recovery finish line was much further away than I had ever anticipated.

After several failed attempts of trying to leap forward and recover as quickly as possible, I



my enemy, and that my chances of reaching that elusive recovery finish line were much greater if I took small steps instead of giant leaps each day. I had to wrestle with my ego a few times, and not feel guilty about taking things slower, especially on days when I was feeling good.

With acute or chronic illness, there is often a fine line between feeling good and tipping over into no-man's land. It's a zone that can leave you flattened and paying consequences for your actions. My biggest lesson was, and still is, learning when to stop and say no.

There were many days when I took steps forward, but there were also days when I took steps back. So, I used the phrase, "Two steps forward, one step back," to keep positivity in my recovery. I knew I was moving in the right direction.

I cannot say it was without frustration—experiencing delays in treatment, feeling like I was not being heard—but I always kept my end goal of recovery in mind. I kept copies of medical records, educated myself, asked



questions—I became engaged in my health care to help me collaborate with my health care team.

My health care team was critical. My neurosurgeon was honest with me about my recovery and the time it would take; my family doctor became my go-to as I navigated the challenges my body faced.

The acute recovery from my swollen brain, brain surgery, and post-surgical meningitis took one year. Being left with a brain injury has a direct impact on your life, and after that year I knew that making time my friend was going to be my biggest ally for years to come.

How did I make time my friend?

- I talked to my ego about not getting in the way of my recovery and health
- Mentally, I had to accept my new normal, be okay with my recovery and not race towards the finish line
- I set realistic goals that allowed me to feel positive about my steps forward
- I planned out my week ahead and rescheduled days where the ‘busy load’ was too high.
- I reached out to my medical team for assistance, my support group for advice, and my family for care and understanding

“ I used the phrase, ‘Two steps forward, one step back,’ to keep positivity in my recovery.”

Five years out from the day my life was saved, I continue to remind myself, that time is my friend. I breathe in the small things, be my body’s own advocate and aim for balance. Not an easy task—but one that is better for me in the long run.

Claire Snyman is an author, blogger and advocate for patient and healthcare collaboration. She’s passionate about inspiring people to put their health in their own hands. She has co-authored a scientific study between neurosurgeons and patients and developed a TEAM Approach for Empowering patients. She was a speaker at TEDxStanleyPark 2018. Find her on Twitter at [@clairehsnyman](https://twitter.com/clairehsnyman).

Learning to Trust Again – My Journey with Drug Intolerance

By Kelly DuBois

My health journey began a dozen years ago, with a spiral that left me feeling I was slowly dying despite the involvement of 20 doctors across two of my hometown medical centers.

My ever-growing list of symptoms included constant weight gain, body aches and pains, unexplained profuse sweating, an enlarged and painful liver, swollen lymph glands, brain fog, memory loss, and increasing body-wide edema. I was diagnosed with acromegaly and underwent pituitary brain tumor surgery and gall bladder removal surgery.

Two years ago, my odyssey led to an answer: I was born with the inability to properly metabolize many medications due to mutated genes in my Cytochrome P450 liver enzyme system. It was all the medications, built up in my system for twelve years, that were making me so incredibly sick! I never had acromegaly; I never needed brain surgery, which resulted in brain damage; I never should have had my gall bladder removed—the medication that was prescribed was never necessary and harmed it.

How did we cure me?

I only needed to stop taking the medications that were metabolized by my polymorphic enzymes. By doing that my profuse sweating completely disappeared, and within the first



six months I lost 50 pounds with no diet or activity changes. In the past two years, I have gone from a size 16 to a size 2. Edema slowly left my body and swelling in the lymph nodes, under my chin, and in my armpits, subsided. It took almost two years, but my liver enlargement slowly dissipated and pain is now very infrequent. My 2-plus page list of symptoms continues to slowly but surely dwindle.

In 2004, when my illness symptoms began, my daughters were two and three years old; we didn't discover what was making me ill until they were fourteen and fifteen years old. I feel guilty that my children aren't the people they could have been because I was never able to be the parent I wanted to be during their formative years.

Learning to trust again.

I remain stunned that so many medical professionals are simply unaware of the cytochrome P450 liver enzyme system and how it works. I lost faith in doctors—but I am slowly learning to trust again.



With that said, this journey has been incredibly sweet. How?

- I've learned that not all versions of the same medications are created equally, and this concept is undervalued. For example, omeprazole will make me significantly sicker than esomeprazole—in my research, I discovered that omeprazole is documented as being a worse CYP2C19 inhibitor than other PPIs.
- I firmly believe that my daughters are the compassionate people they are today because of what they witnessed me go through. I knew I had special kids when they would insist on bringing their favorite stuffed animals to me in bed before heading off to daycare.
- I know now, that you don't have to give up, and there are people out there who will help—you just have to seek them out.
- This knowledge of my genetics will prevent my daughters from going through the medical fiasco I experienced.
- In addition to P450, I learned I have other drug-gene polymorphisms. For example, if I am given Tamoxifen after I reach menopause, it is more likely to cause cancer instead of curing it!

“ I know now, that you don't have to give up, and there are people out there who will help—you just have to seek them out.

- Many of my doctors have said how much they've learned from me, not only about cytochrome P450 drug metabolism but also about what it means when a patient keeps pushing on and telling them they don't feel well. Patient advocacy has a new meaning now for many of my doctors. I am especially appreciative and grateful to my home primary care physician and my nephrologist for being gracious enough to mention how much I've taught them.

I'm surprised I am still alive—and incredibly grateful to have recovered as much as I have. Cytochrome P450 drug metabolism is an under-acknowledged issue, about which I hope that more medical professionals will learn. Patients should never become ill because of their health care.

Kelly DuBois is a technical writer from Rochester, NY. She volunteers on [Mayo Clinic Connect](#), and is also a volunteer advisor for Mayo Clinic National Wellness. She enjoys mentoring and helping to manage [Greater Rochester Robotics FIRST® Robotics Competition Team 340](#) out of Churchville-Chili Senior High School. She continues to participate in several medical research studies at Mayo Clinic and also at her hometown medical center.

Redefining My Life's Purpose ...in a Recliner

By Shani Weber

Ever since I was a young girl I knew I wanted to be an Early Childhood Special Education teacher. My self-identity was being a teacher and my purpose was teaching.

My life was going as planned—until it wasn't. Joint pain and dislocations became more frequent, I worked fewer and fewer hours, and my focus shifted to managing pain, healing joint injuries, and preventing new ones. I was losing my purpose in life—I was losing my self-identity. The orthopedic specialists, physical therapists, my primary care provider, the pain management specialist I saw, worked hard to treat my physical symptoms, trying to increase joint stability to ease my pain. Yet, no doctor or physical therapist addressed my mental distress of losing who I was. Finally, I went to a geneticist and was diagnosed with Hypermobile Ehlers-Danlos Syndrome (hEDS).

Hypermobile EDS, and all types of Ehlers-Danlos Syndromes (EDS), are genetic connective tissue disorders that can affect tendons, ligaments, skin, blood vessel walls, organ valves, the gastrointestinal system, fascia, eyeballs, teeth, and more. EDS can cause pain and problems in just about any part of the body and system. I could no longer teach or do many of my daily tasks. My life switched from toy bags and staff meetings, to needing a recliner, braces, and a situational wheelchair. I went from having purpose, knowing who I was, to barely recognizing myself.



After much reflection I realized that teaching, at its most basic, is helping others and although disabled, I could still do that in my recliner with the help of a laptop. I could provide support and help others with Ehlers-Danlos Syndrome; I could help their doctors and caregivers learn more about types of EDS, and different ways to treat symptoms; I could live a life with the purpose of helping others with EDS live better.

I began by answering questions about EDS in an online support group. I also helped with questions from patients and doctors who would email the Ehlers-Danlos Society's Helpline. I have spoken at conferences and advocated for EDS patients at the NIH, FDA, on Capitol Hill, and at my state capitol with the help of family members. Today I run an EDS support group which I co-founded in my state.

I still live with daily joint dislocations and use many tools, medicinal and non-medicinal, to manage my pain. My electric recliner, which has multiple support pillows and an electric blanket that serves as a giant heating pad, is where I spend most of my waking hours, helping others.



And, my life has a purpose—I'm helping people every day.

I know that many people with EDS or other chronic illness struggle to find meaning and purpose in their life. My hope is that every person with chronic illness can find theirs, and that every doctor will remember that physically disabling conditions can also cause mental and emotional symptoms that make life so much harder. If doctors and other medical practitioners would screen patients for how they may be coping with a chronic illness and offer suggestions or literature that would help patients redefine their purpose in life, then they would be fully treating the whole patient. If a physician does not feel comfortable doing so, or has a patient who needs further intervention, they can still make a significant difference by connecting the patient with a mental health professional who is experienced in working with chronically ill people.

“ I realized that teaching, at its most basic, is helping others (and) I could still do that in my recliner with the help of a laptop.

I feel fortunate to be able to continue my childhood pursuit of helping others, even though the definition of my purpose changed. I live with Hypermobile Ehlers-Danlos Syndrome (hEDS), and I live better knowing my life's purpose is helping others who live with it too.

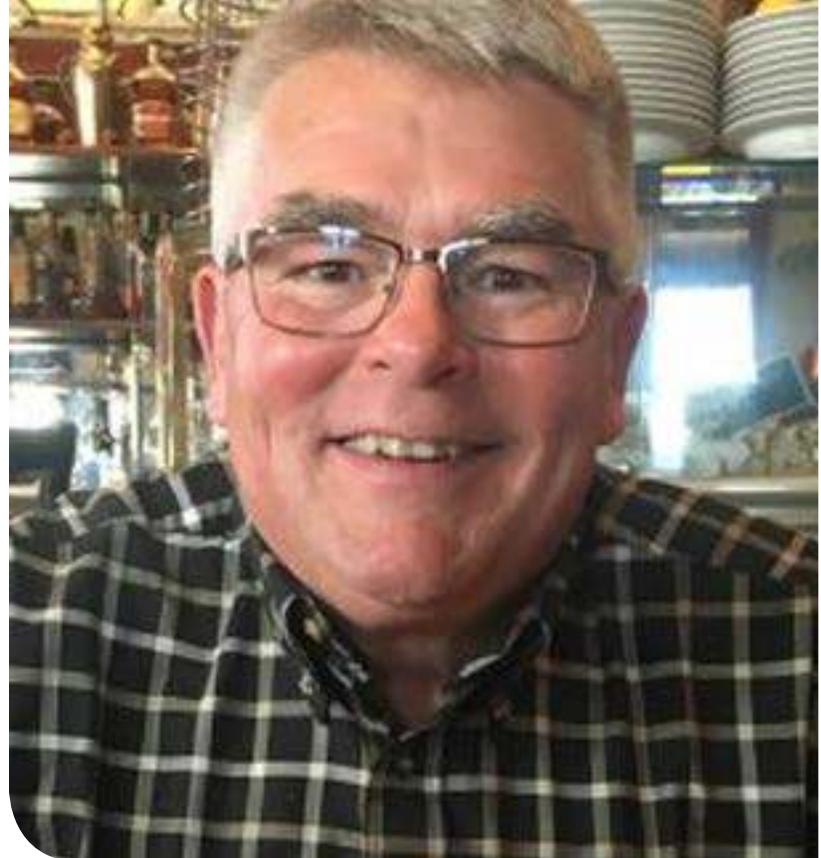
Shani Weber lives in Maryland with her amazing husband, wonderful children, and fuzzy dog. Shani's recliner, where she helps people, is electric and has multiple supportive pillows with an electric blanket that serves as a giant heating pad. She is the local groups and outreach liaison and a helpline advisor with the [Ehlers-Danlos Society](#).

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Eliciting a narrative is a tool that can be taught and practiced in health care, just as we train practitioners in the use of biomedical tools.
@pamressler #ExpertsbyExperience

The Choice and Challenge of Being “Good Enough” – A Caregiving Story



By Scott Phillips

Caregiving arrived without fanfare on her birthday—a June day in 2002—when my wife was diagnosed with brain cancer. It was in one of the small consultation rooms that I first heard the word ‘caregiver’ as my wife lay in a coma in the ICU, while I vacillated between being brave and despondent. There was no training, no employee manual or job description. Just, “You’re her caregiver.”

I was a seasoned business executive and husband of 27 years. I always knew how to manage, especially with the goal of achieving perfect outcomes. I told myself I’d do the same with caregiving.

It was “good enough.”

My wife was discharged after 48 hours. We drove from Minnesota to Illinois and had to spend a night on the road because the rehab facility had no beds available. On that trip back, we realized how unprepared we were to meet her needs. Our daughter had to hold my wife to keep her from constantly opening the door while we were driving. When we stopped to eat at a restaurant, we were asked to leave since my wife was “unsettling” their customers. We grabbed a quick to-go order and ate on the beds in the hotel. It was “good enough.”

On the second day at the rehab facility, reputed to be one of the very best inpatient brain injury facilities in the United States, we were told they wouldn’t be able to provide services to someone with the emotional disturbances that my wife exhibited. She needed additional supervision and our family would have to provide it. It was summer, so our daughter took the day shifts and I took over as soon as I came home from work for the day. It was “good enough.”

Once we returned home, my wife’s anxiety was out of control, despite the extensive daily medicinal cocktail, and her concentration lasted for only minutes at a time. Finding paid help was unreliable and nearly all our friends and family ghosted on us. We made do with the help our children could provide without totally giving up their lives, and with an exhausting revolving door of subpar paid help. But, it was “good enough.”

Managing when caregiving overwhelmed

Even though I was the organization’s top producer, I was fired from my job because the



new manager didn't want “someone with family on their mind.” Nevertheless, for over seven years we managed, “good enough.”

Caregiving was overwhelming—too many things to do, and too few hours in a day to do them. Dust bunnies, dirty laundry, and dishes were constant companions. Shirts looked fine, un-ironed. “Good enough” became my lifeline, especially when I had to deliver 32 doses of medications daily. I kept a pillow on the sofa, which became my punching bag when frustrations ran high. That worked fine until one tough night, when I hit it too hard, and then spent the night cleaning up the living room which had feathers everywhere!

Caregiving costs and scars

Caregiving carries huge societal costs for patients, families, and the caregivers. Approximately 39.8 million caregivers provide care to adults with a disability or illness or 16.6% of Americans.

“ I kept a pillow on the sofa, which became my punching bag when frustrations ran high.

Medical professionals should not ignore the realities of caregiving or leave it up to individuals to figure out how to manage. My wife fought her battle with brain cancer for over 14 years. I'm still struggling with the caregiving scars and guilt I carry in my heart.

“Good enough” shouldn't become just good enough.

Scott Phillips, husband, father, grandfather, and former professional fundraiser, counts his most significant accomplishment in life, his years as his wife's caregiver. Scott volunteers on [Mayo Clinic Connect](#), and is an avid collector of wines from the Napa region. A born and bred Midwesterner, Scott loves family, good friends, and spending time up North. Find him on Twitter at [@onwardtoourpast](#).

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If health care practitioners don't have insight into the stories that the patient brings and shares, recommended care may be clinically correct, but may not be appropriate for the individual. @pamressler #ExpertsbyExperience

The Little Voice in my Head – Escaping My Biggest Enemy

By Alisha Bridges

She always managed to show up right before a big event in my life, “Do you really want people to see your nasty looking skin?” she’d ask me.

“You are going to regret this.”

One of my worst encounters with her was during a dress rehearsal—I was competing in a pageant and none of the other girls were aware of my psoriasis, which covered nearly 90% of my body.

For the evening gown segment, I had picked a beautiful floor-length strapless white dress with sparkly flower embellishment’s which ran down the front and back of the gown. She came to me while I was changing into my gown, “Alisha, you can’t do this. You’ve never had the courage to show your psoriasis before; why start now?” Tears welled up in my eyes. She was right! I stood in the bathroom stall, trying to find the courage to overcome my fears of revealing my patchy, flaky, itchy skin to the world. I took a deep breath, pulled the dress over my small frame, and headed out towards the stage. In a last attempt to stop me, she whispered, “You are going to regret this...”

Jittery and nervous, I made it onto the stage for the dress rehearsal, continuously repeating her words, “You can’t do this...your skin looks horrible...everyone is staring at you in disgust.”



“What’s that on your skin?”

I can recall another time when I was working in Alabama where summertime temperatures can exceed 100 degrees Fahrenheit. During my break, I went out to sit on the trunk of my car to decompress and feel the sun’s rays dance on my face. A co-worker, who I did not know well, approached me for what seemed like general conversation. After his initial greeting he asked, “What’s that on your skin?” As I fumbled to explain, he cut me off, “You know, you’re pretty, but your skin is ugly.” His matter-of-fact words jumped at me like a deer in headlights. The long sleeves and pants I wore couldn’t conceal the psoriasis on my hands and neck.

I heard her voice again, “He’s right; look at you, trying so hard to hide your psoriasis, and people can still see it.” Overwhelmed with those same panicked feelings I had during the pageant, I ran to a stall in the restroom and cried for the rest of my break.

Holding me captive

She appeared often. Every time I had to push past my comfort zone with psoriasis, she was there to remind me why I shouldn't, why I couldn't, and all the negative things others may feel. I couldn't escape her taunts because she was me. She was the voice inside my head, telling me horrible things. She was anxiety and panic. She was fear. She consumed my confidence and held me captive. In the beginning, I used to think of her as a necessary presence—to remind me of the misunderstanding ways of the world. I thought this was tough love. I thought this voice inside my head was normal.

Silencing her whispers

In 2011 I attempted to end things with her in a blog titled, "My suicide letter." It was an attempt to say farewell to the voice that plagued my soul, the voice that had suffocated my life. The day of that letter, I became a new woman. NOW I stand up to her. NOW I can combat that ruthless voice. NOW I know the hurtful, negative things I hear are not true, but come out of internal insecurity—it's what anxiety feeds on.

“NOW I know the hurtful, negative things I hear are not true, but come out of internal insecurity—it's what anxiety feeds on.”

She hasn't vanished completely, and sometimes still appears—it takes an army to combat my inner self! The biggest arsenal has been the National Psoriasis Foundation. When I decided to make the foundation's resources an ally, my battle against psoriasis totally changed. I finally found the courage to tell my story; but most of all, I realized I was no longer alone.

Alisha Bridges is a freelance health writer on the topics of sexual health, skin care, and psoriasis. She has lived and thrived with psoriasis for over two decades. Alisha is the creator of *Being me in my own skin*, a site dedicated to sharing what it's like to live with psoriasis. She is also a student at Georgia State University, pursuing a career as a physician assistant with a focus in dermatology. Find her on [Twitter](#) and [Instagram](#) @alishambridges.

A Nothing Day: Self-Care for Caregivers

By Harriet Hodgson

“Today I’m going to have a Nothing Day,” I blurted to my husband. “I’m going to sit on the couch, put my feet up, read if I want to, take a nap, or stare straight ahead.”

My wheelchair-bound husband turned to me and replied, “I understand.”

He did understand because he has participated and watched me care for three generations of family members—we’re a caregiving team. Glad as I am to be a family caregiver, it’s a tiring, stressful, and demanding role. In my 21 years as a family caregiver, experience has taught me the importance of self-care.

What is a Nothing Day?

It would be a day to consciously slow down and pamper myself. No grocery shopping. No running errands. No upsetting newscasts. I would put on the brakes and revel in the quiet. I would listen to my self-talk and take stock of things. A Nothing Day would include basic care to ensure the safety and well-being of my husband.

“You’ll get your meds and your meals,” I assured my husband, “but the meals will be simpler.” My husband is fascinated by the history of World War II and watches war programs constantly. I asked him to turn the volume down. He nodded in agreement and activated the television



caption feature. Later, I realized the quiet was healing.

Planning an off-day

Caregiving experts and organizations stress the importance of self-care; without it, caregivers risk illness, aloneness, and depression. Certainly, I didn’t want this to happen to me. The idea of an off-day had been rattling around in my mind for weeks.

I read articles, including one by Barbara Markway, Ph.D., who writes for *Psychology Today*. She divides self-care into five categories: Mental, Spiritual, Emotional, Physical, and Social. I liked the first four categories but eliminated the social one because I yearned for peace and quiet. Although I need socializing, I just didn’t need it now. I started planning the day and what it might include.

Declaring a Nothing Day has distinct benefits. Planning the day gave me something to look forward to. Slowing down was a proactive step and would help me destress. If all went well, the



day would energize me for caregiving days to come.

Telling your loved one

My husband is a retired physician and we've been married for 60 years. I knew he would understand the Nothing Day idea, but other care receivers may not. Bringing up the idea can make a loved one nervous. Still, a loved one needs to know your plans. The Family Caregiver website tells caregivers to practice self-care early and not wait until they're overwhelmed, exhausted or facing major health problems—good advice for all caregivers.

How can you share your news? The answer to this question depends on your loved one's health. Pick a good time, not when your loved one is tired, hungry or upset. If your loved one has memory disease, you might have to repeat yourself several times. You may wish to make a sign that says Nothing Day, with the day of the week, and date on it; circle the day on a calendar as well. Allow enough lead time to give your loved one opportunity to process the thought.

Most importantly, assure your loved one that her or his basic health needs will be met.

How I spend my Nothing Day

I try to have a Nothing Day once a month. I listen to my body which often lets me know when I need this day. I can barely walk when I get up in the morning because I have bursitis and arthritic hips. It takes an hour and over-the-counter medication to get my creaky body going, and if my pain worsens, I know it's time to slow down and take care of myself. I've developed a repertoire of quiet activities:

- Meditation
- Listening to music
- Logging into reliable caregiving websites

“Most importantly, assure your loved one that her or his basic health needs will be met.”

- Writing caregiving affirmations
- Reading my favorite magazines or the mystery novel I've wanted to read for weeks
- Taking a long nap and not feeling guilty about it
- Watching birds come to our backyard feeders
- Baking cookies (I love baking)
- Thinking about ideas for future books

Although my quiet days include some caregiving tasks, the tasks are simple and I focus on slowing down. Such days have become part of my normal routine. I'm blessed to have a husband who understands me and to be his primary caregiver. For us, every day is a miracle. As I approach my 22nd year as a family caregiver, I feel deserving of Nothing Days—and you are as well. Put this day on your calendar and start planning now!

Harriet Hodgson has been a freelance writer for over 38 years. She is the author of 36 books and thousands of articles, and has also appeared on radio talk shows and dozens of television stations, including CNN. She has been a family caregiver for 21 years and her recent work focuses on this topic. Visit www.harriethodgson.com to learn more about this wife, grandmother, caregiver, and author. Find her on Twitter at [@healthmn1](https://twitter.com/healthmn1).

Good Cancer? It's Still Cancer

By Aleka Leighton

“ I still suffer from feelings that they lied to me.

Almost six years ago, the doctor told me I had thyroid cancer. “But don’t worry,” he quickly added, clearly noticing the color draining from my face, “you are going to be fine. You have time to find a surgeon, it’s not the worst cancer, and you have the GOOD CANCER.”

With those final words, my mind stopped processing any more information. The only words I could hear—to think, to walk, to move, to survive—were GOOD CANCER. The part where my doctor described the removal, the radiation, the whole-body scans, didn’t reach my ears. It’s incredible how the mind works when confronted with a situation that makes you feel afraid, panicked, and overwhelmed.

Connecting with others

Three months after hearing those words, I realized how much of a “newbie” I was to thyroid cancer. This small gland controls so much in the body! I needed to educate myself, look for support groups, and meet others like me. I found many survivors and newly diagnosed patients with similar issues and concerns and quickly became as much of an expert as I could be. I learned many of these patients also felt their diagnosis was diminished by the characterization of thyroid cancer as a GOOD CANCER.



Thyroid cancer is real cancer

Thyroid cancer is not the “good kind.” No cancer is! I couldn’t understand why they used that term, or why they continue to use it. I still suffer from feelings that they lied to me. Living with thyroid cancer has not been an easy journey—surviving this cancer means dealing with secondary effects and changes for the rest of your life. As a survivor, you depend on hormone pills, continuous scans, and blood work; but the worst and hardest part of this journey is that doctors, nurses, caregivers, and family need to believe and understand your symptoms. When a surgeon removes the thyroid gland, it is not the end of a health ordeal, but the beginning of a new person—that person may sometimes be likable, and at other times be very unlikable, because they are constantly dealing with hormone issues, weight problems, blood pressure issues, palpitations...the list goes on.



In hindsight

Looking back, I think my first approach with the medical team helped me make decisions that affect how I research and ask questions today. Back then I was confused, afraid to ask questions. I thought I wasn't supposed to feel this way. I didn't give my mind and body time to suffer or adapt to the new me because I wasn't supposed to feel like that; my cancer was the GOOD CANCER. I didn't want to become the bothersome patient or the crazy hormone-woman who complained all the time. It was only after meeting others on the same journey, I realized I needed to take an active part in my own health care.

Thyroid Cancer is a hard cancer, like any other, so please, don't diminish it or the struggle. My suffering is real and I don't need to feel guilty or apologize for only having thyroid cancer.

Finding purpose

They say things happen for a reason, and I believe that my reason is to be a voice for

“ It was only after meeting others on the same journey, I realized I needed to take an active part in my own health care.”

other patients with thyroid cancer. By talking about my experience, I can educate and help others open up and be less afraid or ashamed to share symptoms I know are very real. We can start by saying thyroid cancer is more treatable, rather than calling it a GOOD CANCER.

I finally stopped feeling guilty about only having thyroid cancer, and gave my body and my mind permission to suffer. I've finally made peace with the new me.

Alexandra “Aleka” Leighton is Chilean but grew up in Venezuela. She is a journalist who loves to cook, read, run and lives with her husband in Miami, FL. Aleka works to create awareness about thyroid cancer in Hispanic and other communities. Find her on Twitter at [@AlekaLeighton](https://twitter.com/AlekaLeighton).

This Four-Time Cancer Survivor is a “Head and Necker for Life”

By Maureen Jansen

I identify myself as a head and neck cancer patient, and not just because of my scarred face—I don’t like calling myself a survivor in case I jinx it. Head and neck cancer never goes away. You are left with scars, defects, dry mouth, gaps where your teeth used to be, and often, ongoing checkups and medical procedures.

When I joined a head and neck cancer support group in 2015, I became committed to providing support and advocating for fellow patients. Oddly enough, this has been one of life’s greatest gifts for me—I’m a “head and necker” for life.

Second opinions matter

The cancer started years before diagnosis in 2007, with a painful ulcer on my tongue that wouldn’t go away. After being told by a visiting oral surgeon that it was just a harmless lichen planus lesion, my general practitioner and I treated the pain and didn’t look any deeper. What annoys me now is that he and I knew we should have sought a second opinion. We did so with my ovarian cancer and that worked well; but this time we deferred to the authority of the oral surgeon.

So, 2007: a minor operation leaving behind some dodgy tissue around the margins; a



slight lisp, a return to work as a teacher—no big deal except that it was hard to read out the school notices first thing in the morning.

Cancer pushes the limits

And, two years later: a recurrence that really pushed me to the limits! Serious tongue cancer can lead to a gruesome all-day surgical ordeal. Usually, the patient has a portion of the tongue removed (50% in my case), and a flap of tissue from the forearm is sewn into place, together with the blood vessels that go up the inner arm. The flap has blood flow but no nerves. To cover the wrist wound, a thin slice of skin is taken from the thigh. Along with this, a neck dissection is performed to remove a number of lymph nodes. This is truly a horrible surgery requiring multiple drains, a doppler device to check blood supply to the flap and, worst of all, a tracheostomy so the patient can breathe through the neck because the mouth is swollen—no talking is permitted for 8 to 10 days.



Despite all this, I recovered well. I attribute my bouncing back quickly to my love of exercise; a little bit more walking each day until you return to normal fitness.

Taking cancer to another level

The year 2014 saw a life-changing event, a recurrence, low in the inner cheek—the buccal mucosa—not far from a previous tumor. I underwent a similar operation without the tracheostomy—a quicker recovery from surgery, then radiotherapy that took me a year to get over.

During head and neck cancer radiotherapy, your head is clamped down in a mesh mask and the inside and outside of your face, neck, and mouth are burned by the treatment. This takes cancer treatment to the next level. Some people have chemo with the radiation, making it a lot worse, but I didn't need that and actually found the caring nature and everyday routine of the radiation oncology unit comforting and supportive.

A new normal

After finishing these treatments in May 2014, I was faced with a new normal: a cut nerve, no front teeth, a sucked in lower lip, a deep, crooked scar on my chin and “oral incontinence.” I could no longer hold fluid in my mouth and had to hold a thick cloth to my mouth while eating and drinking. I had trismus (limited mouth opening). I could no longer eat anything but the softest of foods

“ A major contributing factor to a better life has been joining a support group.

and that also had to be covered in gravy or custard.

Some of these things could be worked out. Dentures were uncomfortable but they gave me the ability to smile sweetly. I kept a supply of face cloths by my side at all times. I had to work hard to pull myself out of isolation. A major contributing factor to a better life has been joining a support group, and helping to put it online for New Zealanders and overseas patients. My English teaching skills were put to good use, taking down minutes of meetings, publishing a newsletter, helping run a website and blog, and starting a busy Facebook support group.

Supporting others online is fulfilling. Today, the sense of connection and purpose from connecting with others in online health support groups has made my cancer a benefit rather than a curse.

Maureen Jansen, 71, a former English teacher and four-time cancer survivor, is a grandmother of two and mother of three. She had ovarian cancer in her 40s, and head and neck cancer with recurrences in 2007, 2009 and 2014. She is fit and well, but scarred and slightly disabled from all the treatments. She lives in God's Own Country, New Zealand. Find her on Twitter at [@HNCMaureen](https://twitter.com/HNCMaureen).

Coping With Loss of the “Health Privilege”

By Danielle Ripley-Burgess

For some people, the only life they’ve ever known is full of suffering, disease, and pain. I am not one of those people.

I was born a healthy baby in December 1983, and for most of my childhood, I stayed that way. I never broke a bone and I rarely got sick. I did contract chicken pox alongside my brother when I was in kindergarten. Although we were itchy, we sure were cute—two dark-headed, pale little kids with matching red dots all over us. My mom couldn’t help but take pictures.

In 3rd grade, an unfortunate run-in with the bathtub opened the door for my first ER visit. I left with stitches and a permanent scar that still runs through my right eyebrow. But after that incident, I had no need to return to the hospital for many, many years.

Throughout my childhood, I was rarely a patient. I lived a very healthy life through an unconscious filter (of which I had no idea), until a few weeks after my 17th birthday. There I was on a Tuesday night, working at the local library when my parents walked in to give me the news - I had stage III colorectal cancer.

It would take years for me to realize I lost more than my innocence, my youth, and carefree living that night—I also lost my “health privilege.”



Health Privilege Defined

Fellow ePatient Carolyn Thomas wrote on the idea of healthy privilege in a column for Center for Advancing Health, where she quotes Dr. Becker-Schutte who adapted the definition of white privilege to explain “healthy privilege”:

- A right, advantage, or immunity granted to or enjoyed by healthy persons beyond the common advantage of all others; an exemption in many particular cases from certain burdens or liabilities.
- A special advantage or benefit of healthy persons; explained by reference to divine dispensations, natural advantages, gifts of fortune, genetic endowments, social relations, etc.
- A privileged position; the possession of an advantage healthy persons enjoy over persons with illness.
- The special right or immunity attaching to healthy persons as a social relation; prerogative.



Like many other social privileges, those living with a “healthy privilege” are often unaware of it. Because this concept is not often discussed, those living without a “healthy privilege” are often unaware of it as well.

We recognize the irritations that nag us when our lives must be adapted to chronic health conditions and “new normals.” We accept the need to budget to afford medical supplies and procedures. We pack in case something goes wrong. Even the way we schedule vacations is oftentimes different from those who don’t think twice about booking a non-refundable trip! Yet, we’re often unaware that our lives operate so differently from others—not because of the surgeries and scars—but because of this concept of privilege.

From Unaware to Aware

I didn’t realize I was grappling with the loss of my “health privilege” for many years. I hadn’t realized I needed to permit or allow myself to be okay, that my life would always look somewhat different from others who’d never faced the loss of health. In all honesty, it took sitting on a comfortable couch, across from my counselor, who helped me see what was happening.

“We can easily take health for granted and miss what others are experiencing when we don’t realize we carry a health privilege,” said Barbara Lucas, MS, LCMFT. “The lives of those who’ve experienced a loss of health can look very different from the lives of those who’ve never experienced it.”

Talk about a lightbulb moment! Not only did life start to make sense again, but the anchor of grief that sat deep inside of me finally began to come up.

“ I appreciate being unique and cherish the empathy it has brought me for other patients and families.

Empathy for Self

These days, even though it’s without the “healthy privilege,” I live with peace. I appreciate being unique and cherish the empathy it has brought me for other patients and families. I hope they too can find the words to articulate the depth of their loss—it’s a powerful experience and one that’s given me a lot of mental and emotional healing.

I also hope providers will extend the utmost patience to those filling up their waiting rooms. The experience of being a lifelong patient cannot always be articulated through charts, questionnaires, and forms. The patient experience goes deeper than needles, tubes, tests, or procedures. When dealing with a life-altering and/or life-threatening medical situation, we’re not just talking about sickness or health...we’re actually dealing with privilege

Danielle Ripley-Burgess was first diagnosed at age 17 and is a two-time colorectal cancer. She is a content strategist with the advocacy organization [Fight Colorectal Cancer](#). Surviving cancer, parenting a biracial adopted child, and marrying her high school sweetheart give her plenty of stories to share on her blog at [DanielleRipleyBurgess.com](#). Find her on Twitter at [@DanielleisB](#).

PS: Enjoy your life

By Rosemary Huckleberry

A multiple organ recipient grieves for a life lost, until a special message arrives

When routine labs indicated abnormal liver function numbers, my doctor referred me for further testing. I was diagnosed with Primary Sclerosing Cholangitis (PSC), a chronic liver disease with no known cure except for liver transplant surgery.

I was frightened beyond words, but with my doctor's support, I concentrated on staying healthy by focusing on a healthy diet and increased physical activity. With no bothersome symptoms and routine monitoring, I successfully put the thought of surgery out of my mind for nearly seven years.

Fear

In September 2008, the doctor informed me that my cirrhosis had progressed and I would need to have a liver transplant...and soon! I was placed on the organ transplant waiting list and the fear of major surgery dominated my mind again; for the first time, I realized that my life, my future, would depend on the donation of a healthy organ from another person. And, that person would have to die so that I could live. For me, this was a moral and ethical dilemma. My pastor guided me, helping me understand that through organ donation, a person (while living) makes the decision to give his/her organs to someone in need after he/she no longer needs them. It is a person's final act of human love. I decided then, that I would honor this gift if it was offered to me.



Guilt

Over time my health deteriorated as my symptoms worsened with the advancing cirrhosis. My life was on hold. When my kidneys failed suddenly and I needed dialysis, I was afraid that time was running out. I was now in need of both a liver transplant and a kidney transplant, and I began to pray and hope I would receive a transplant soon. This rekindled a sense of guilt and became an even bigger dilemma for me—did I want someone to hurry up and die? It was time to rethink, to refocus on what I was hoping and praying for. Early one morning in April 2009, I received the call from my transplant surgeon—they had organs for me.

Relief

The surgery went well, my new organs began to work right away, and I was beginning to feel like a healthy person again. Family visits were joyful, and I remember hearing the sound of laughter—I looked forward to a future with my loved ones. But I envisioned another family somewhere, grieving. A life had ended, and another life was



beginning. On one hand, I was overjoyed and wanted to shout, “I’m alive!” On the other hand, I grieved for the family who had just lost a loved one—my organ donor.

Several months later, I wrote a letter to my donor’s family—it was difficult to find the right words. How does one send condolences, and say thank you at the same time? Relieved, when I finally dropped the letter in the mailbox, I silently wondered how they would receive my message.

Peace

One day, the mailman handed me a special delivery envelope—it was from my donor’s family. Clutching it, I had to sit down for a while before I could open it. Carefully opening the envelope, I slowly read the contents with tears



How does one send condolences, and say thank you at the same time?

in my eyes. The last words, “We want you to enjoy many years of a happy life,” gave me the resolution of any guilt that I still felt. A sense of peace came over me as I read the hand-written message and learned a little bit about my donor—a day which I will forever treasure.

Joy

I received the gift of life and more! I was given the permission to enjoy my life. And I do, every day.

Rosemary Huckleberry, a simultaneous kidney/liver transplant recipient, lives in central Kentucky and is a volunteer Mentor on Mayo Clinic Connect. Her favorite pastimes include knitting and crocheting, and she has started a prayer shawl ministry at her church. Rosemary loves solving Sudoku puzzles, playing the violin at church, and taking annual hiking vacations with her husband.

Stepping into Self-Advocacy

By Kate Sheridan

When footwear becomes a tool for self-empowerment

On my first day of 11th grade, I suffered from a cardiac event. My dad called 911 while I focused on trying to breathe. The Emergency Medical Technicians (EMTs) arrived quickly and loaded me into an ambulance. Laying on the stretcher, I hazily remember seeing a firefighter above me. “Nice sneakers,” he said, with a grin.

More than a decade ago, I was diagnosed with a complex case of Lyme disease which triggered an autoimmune condition, a cardiac condition, and pain syndrome. Over the first three years, I was referred to more than 30 doctors, given 15 different diagnoses, and was hospitalized 5 times. As the disease progressed and my pain levels became excruciating, the illness began to undermine parts of my identity. I went from being a straight-A student to being unable to read or write; from a competitive athlete to bedridden, and from an extrovert to feeling isolated.

Having a controversial illness like Lyme disease only made the process harder. I was told I was imagining my symptoms, or making up my condition to avoid going to school. I would try and hide my central ports and IV bags so that I could attend social events as a “normal” person—only to become bedridden for weeks after, to recover the spent energy. With impaired brain function, I was exhausted



at doctors appointments, trying to remember what changes I needed to share with my health care providers. As my condition worsened and emergency situations became more common, I began to dread the panicked visits to the Emergency Room. The first few visits all saw the same pattern—I was a diagnosis, passed from hand-to-hand until discharge.

Then, when conditions hit a real low, I ordered a pair of oversized, multicolored sneakers. The shoes gave me a talking point with my providers and a reputation in the Emergency Room. With every new diagnosis and treatment, the sneakers became louder: after my first blood transfusion, I ripped out the shoelaces and replaced them with motley cloth scraps. By the time I had lost the ability to run, there was neon paint splattered across the firework designs on the leather.

The sneakers helped providers engage with me as a person. When I wore them, the EMTs, nurses, and doctors treating me would notice them and comment. This would allow me to start a conversation and make jokes about



my wild sneaker collection. Suddenly, I was no longer just a patient; I was the goofy kid with the weird sneakers—just like their kid or niece or sibling. This personal connection influenced some important aspects of my care—like taking more time to be gentle while inserting an IV—and some less important things—like getting extra snacks! Doctors were willing to hear my whole story and not just a summary. When I had my shoes, I had my voice, and for the first time, accidentally, I had become an advocate for myself!

The future of medicine seems focused on health technology, robotic surgeries, telemedicine, implants, and transplants...and rightly so. But in my experience, finding simple and meaningful ways to connect can be just as powerful. Eight years after that ambulance

“ When I had my shoes, I had my voice.”

ride, my perspective on health care has become more complex, policy-oriented, and data-driven. But I also appreciate that my first steps into the world of health care imprinted me with the knowledge that individualized, personal care will always be at the heart of good medicine.

Kate Sheridan is a patient empowerment advocate, speaker and recent graduate of George Mason University. Kate's experience as a pediatric chronic patient inspired her to become certified as an Emergency Medical Technician, and to pursue a B.S degree in Health Administration and Policy, with a long-term goal to increase patient empowerment and improve patient outcomes. She is currently pursuing a master's degree in Comparative Social Policy at the University of Oxford. Find her on Twitter at [@kate_sheridan1](https://twitter.com/kate_sheridan1).

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Patients understand the day-to-day realities of health challenges in a way clinicians can't. @FarrisTimimi #ExpertsbyExperience

Straight from the Doctor's Mouth – My Cancer Diagnosis



By Justin Birckbichler

After the customary, “Drop your pants so I can examine you,” the urologist, who I knew for barely five minutes, looked me in the eye and continued, “So I am going to be straight with you. You have testicular cancer.”

Wow! I had ended up in the urologist’s waiting room after detecting a mass on my left testicle during a routine self-exam. Even though I internally suspected this, ever since I first felt the lump and did some research online, it was still very different to hear it from the doctor. Furthermore, I just visited my family care doctor eight days ago—I went from having an “area of concern” to being a cancer patient in just more than a week.

When I tell this story, most people are taken aback by how blunt the urologist was. But, I appreciated how straightforward and frank he was with me—in contrast to my family doctor who, after confirming that there was a lump on my testicle said, “It could be any number of things: a cyst, an infection, or it could be a cancerous mass.” A few days later, despite an ultrasound detecting a solid mass, the same doctor still hesitated to say it was cancer. She prescribed an antibiotic, to rule out the slim chance of it being an infection, and also referred me to the urologist.

Back in the urologist’s office, the visit continued. Based on his brief examination and the ultrasound, he was 99% certain it was cancer. “Is this something I get a second opinion on?” I asked.

“In most cases, I tell my patients to get a second opinion. In your case, we don’t have time,” he replied.

The good news about testicular cancer is that it’s treatable. While 1 in 250 men will develop this cancer, the 5-year survival rate is 95%. The bad news is that it’s very aggressive and can quickly spread to other parts of the body and become more complicated. The doctor said I was smart and caught the symptoms early.

“So, what’s next?” I asked him.

“Surgery. We need to remove your testicle immediately. We can probably get you in tomorrow.”



Double wow! Not only was I a cancer patient, but I was also upgraded to surgery patient! Again, it was refreshing to have such direct answers, but it was a lot for me to process. I said I couldn't commit to surgery the next day and needed some time to think. He understood but reiterated that I had to move fast.

While I grappled with the prospect of surgery, not to mention losing a testicle, one thought struck me as vital in this journey—the doctor's direct method of communication. He gave me answers—maybe not what I wanted to hear, but what I believed was necessary.

I encourage all doctors to follow his lead. It amazed me, in the beginning, my cancer was treated as an afterthought rather than a definite possibility. I understand that sometimes it may be better for physicians to understate some conditions like this, rather than get patients worked up only to find out it may not be cancer. However, the inverse could be a life-changing mistake.

“ The doctor said I was smart and caught the symptoms early. ‘So, what's next?’ I asked him.

I appreciated how direct and frank the urologist was in helping me find answers, and I decided to do the same. I called him back and gave him my answer: I was ready to get the ball rolling on surgery.

Justin Birckbichler is a men's health activist, testicular cancer survivor, and the founder of aBallsySenseofTumor.com. From the time of his diagnosis in November 2016 at the age of 25, to being cleared and in remission in March 2017, he has been passionate about sharing his story to raise awareness about testicular cancer and to promote open conversation about men's health. Connect with him on Instagram ([@aballsysenseoftumor](https://www.instagram.com/aballsysenseoftumor)) and on Twitter ([@absotTC](https://twitter.com/absotTC)).

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Focus on the tapestry that is woven by the patient stories, for there is more to be learned in listening than in talking. @FarrisTimimi #ExpertsbyExperience



A Call to Courage

By Laura Kieger

When the family health history may still be the most important piece of the puzzle

Now is not the time to get scared.” Those are the words of Dr. Howard Kaufman, one of the scientists who approved a gene-editing human study conducted in California in late 2017. The patient, a man named Brian Madeux, suffers from a rare inherited metabolic disease, and this clinical study is the first attempt by U.S. scientists to edit genes inside the body of a living human. Their tool? A gene-editing technique much like CRISPR/Cas9 technology that is revolutionizing biomedical research at a feverish pace.

I was eleven when my grandmother first told me she thought there might be something wrong with my mother’s family. Two years later, in 1972, that “something” was given a name—Familial Adenomatous Polyposis or FAP—a rare autosomal dominant genetic condition caused by germline mutations in the adenomatous polyposis coli (APC) gene. We became a family that carried more than a genetic mutation; we were now a “cancer family.”

It wasn’t until 1979 that I sat down with pencil and paper and drew the circles, squares, and lines connecting loved ones with myriad cancer



diagnoses. It was my first crude attempt at a medical family tree or “pedigree chart.” I carried that piece of paper with me to doctors’ appointments for the next twenty years. For all the advances in health care, genetics, and personalized medicine, the family health history may still be the most important piece of the puzzle in aiding health care practitioners to determine one’s lifetime risk of developing cancer.

To help focus attention on the importance of family health history, the U.S. Surgeon General, in cooperation with the Department of Health and Human Services and other agencies, has launched a national public health campaign called the Surgeon General’s Family Health History Initiative to encourage all American families to learn more about their family’s medical history. The Surgeon General’s “My Family Health Portrait” is an internet-based tool that makes it easy to record your family health history.

Of course, in order to effectively utilize these valuable tools, one must collect and organize



their family's health information—which includes talking with family members. Family gatherings are a great time to broach the subject. Some may be reluctant to discuss medical issues, so it's important to be sensitive to potentially painful memories or perhaps denial that the disease may “run in the family.”

Once you've gathered your family's health history, and it suggests that you might have inherited a risk of cancer or other diseases, you should first consult with your health care practitioner. For people at risk of developing cancer, this knowledge, coupled with genetic testing, can be lifesaving.

Going back to Dr. Kaufman's work, it's worth mentioning that gray areas exist when contemplating cutting-edge technology to “fix” a bad gene or “repair” a genetic mutation. But for families at risk for inherited cancer conditions like FAP, Lynch Syndrome, and BRCA 1 & 2 genetic mutations, answers have been decades in the making. For us, gene-editing technology that targets human DNA and acts like molecular scissors to cut and replace disease-causing genes with healthy ones is, well, unbelievable.

“ For people at risk of developing cancer, this knowledge, coupled with genetic testing, can be lifesaving.

James D. Watson, the American co-discoverer of DNA structure said it best in a 1999 Time Magazine article— “Moving forward will not be for the faint of heart. But if the next century witnesses failure, let it be because our science is not yet up for the job, not because we don't have the courage to make less random the sometimes most unfair courses of human evolution.”

Creating, updating, and sharing your family's health history will remain a reliable and valuable tool for generations to come—acting upon it is even more critical. Now that new technologies are here, we must be brave and determined; now is not the time to get scared.

Laura Kieger is the author of *Summer's Complaint: My family's courageous, century-long struggle with a rare genetic cancer syndrome, a story rich in love, courage, resilience, and hope.*

Laura and her husband Bill raised their three kids, Alexander, Kelsey, and Adele in the beautiful state of Minnesota. Visit her website at www.laurakieger.com. Find Laura on Twitter at [@lkiegerauthor](https://twitter.com/lkiegerauthor).

The Art of Slowness: The Abstract and Concrete in Chronic Illness

By Janet Kozachek

The desire to have control over one's environment, and to have access to the fruits of life and labor, burns consistently in every heart. In the face of health adversity, realistically evaluating your ability, and pacing accordingly, is my best approach to achieve success. But this can be a challenge within our cultural paradigm of instant gratifications and unrealistic positivism.

Nevertheless, through examples of slowly articulated work, and delayed yet accomplished gratifications, I will illustrate how, at least in this patient's life, the slow rhythm of working gets things done.

The rate at which I've completed tasks, while managing Ehlers Danlos Syndrome, has varied with the degree of debility. There were years when I was largely confined to the home—and mostly to the bed. During those years I still managed to sit propped up to complete drawings. Early on, in a post-viral chronic fatigue, I was only capable of painting about two square inches a day.



So that's what I did—a week's worth of effort yielding a small painting. When postural orthostatic tachycardia and intolerance made standing, or even sitting problematic, I splattered paint on to a canvas while lying down.

Understanding boundaries and setting goals within them is something of an art form in itself and requires a concerted effort on the part of the patient, family members, and caregivers. After addressing a number of spinal issues, for instance, I became much more physically active. One day I decided that, ready or not, I would tackle a rather demanding project. Our property had been damaged by a hurricane that had overturned large trees. Cement walls toppled, hillsides were gouged out, gardens plowed under, and a large cement patio in the corner of the yard was cracked beyond repair. After a day of slack-jawed disbelief and utter despair, I rolled up my sleeves and set to work.

Why would a connective tissue disorder patient, with craniocervical instability and unreliable stamina wish to do this? I suppose this goes



back to that fundamental need to know that one's efforts can yield concrete results—even if that requires significantly more time to realize.

Releasing thick slabs of concrete from their brick underpinnings, I began the task of breaking them up. It took several whacks but I finally broke up a 15-foot cement slab into four blocks. But how do I move these blocks?

The massive size and weight of the concrete blocks was daunting, yet I couldn't give up. Standing back, I noticed that the asphalt driveway, below the cement, was on a steady decline. Perhaps I could alter the square blocks to make them round boulders and roll them out? And that's what I did!

Inspiration can come from unusual sources. The only artwork I had completed during my epic cement patio removal, other than giant painted snakes for a march in support of science, were paintings of large egg shapes. For one of the paintings, I used sized paper



"Egg of Granite with Magnolia Leaves"

“ Inspiration can come from unusual sources. ”

and a number of large and small stamps. The small round stamps were inspired by the granite stones found in the cement aggregate.

Looking at them one might think that they are symbols of life or fertility. But they were inspired by the shapes of the huge cement slabs I could remove on my own—only after I carved them into egg shapes and rolled them down my driveway. In the very center of my concrete egg, I placed a red print from a stone seal that was carved for me by a Chinese calligrapher some decades ago. The words read, *"Persist until the very end."*

The delayed gratification of getting this done? It was a slow realization of will. It is my hope that those in healthcare professions catch up with the slow realization that patients do have the will. Let's help them find their own reasonable ways.

Janet Kozachek is an internationally trained and exhibited artist with a Master of Fine Arts Degree in painting and drawing from Parsons School of Design in New York, and a certificate of graduate study from the Central Academy of Fine Art in Beijing (CAFA). She is a well-known mosaic artist, and was the founding president of the Society of American Mosaic Artists. Currently, she is working on an illustrated book, *You Look Great! Making Invisible Disease Visible*. Her blog, *Art of Janet Kozachek* has updated art, stories and articles.

Surviving, Then Thriving

By Erin Moriarty Wade

On a cold dismal Wednesday afternoon, I found myself sitting at the children's hospital for the third day that week.

My two-year-old was throwing a huge fit because he wasn't allowed into the therapy pool where my daughter was having a session with her physical therapist. My nine-year-old son was walking home alone from school, in the rain to an empty house. I thought anxiously about how we had to check into a different children's hospital the next day for my daughter's infusion. My mind wandered to the freelance writing gig I had turned down; I really wanted that job, but knew I couldn't take it with the rigorous schedule of medical appointments.

"If you're happy and you know it, clap your hands," sang a little voice.

I looked over and saw a little girl who was waiting for her turn in the therapy pool. She had a prosthetic leg and her other leg grew only to her knee, where it had a tiny foot that faced backwards.

"If you're happy and you know it, stomp your feet," she continued, giggling and leaning on her crutches to stomp her prosthesis. Tossing her blonde curls, she smiled back at her mom. The little girl stopped me in my tracks. How could I be feeling sorry for myself while she was so joyful!



That day, I realized I had to find a way to survive... and thrive in my new normal. I needed to find a way to take difficult experiences, the constant slew of medical appointments, our daughter's new challenges, and not let them consume me.

Our lives changed drastically when Ansley, our daughter, got sick. My husband and I were blessed with three beautiful, healthy children (who were 8, 5 and 1 at the onset of Ansley's illness). I worked part-time, writing healthcare content for a hospital, and I loved the balance of professional work and mom duties.

The summer before Ansley started kindergarten, she began experiencing strange and terrifying symptoms—from stiffening in her body and leathery skin, to huge lymph nodes and partially paralyzed hands. We were thrown into a whirl of countless appointments with pediatric specialists, seemingly endless tests, diagnostic procedures, a biopsy, surgery and more.

After many months, she was diagnosed with a rare and serious autoimmune disease. It was scary, frustrating, depressing and exhausting.



Eventually, we found an expert who devised a treatment plan, and we enrolled in a long-term research study. I learned how to give injections and administer an IV at home—it was a difficult two years.

It's been about three years since Ansley got sick, but thanks to medical specialists, powerful drugs, countless sessions of physical and occupational therapy, and moving to a warmer climate, she is much better. Doctors hope that she will be in remission after five years.

Although Ansley still struggles with tough side effects and some pain, her hands are completely back to normal, and she can run, bike and play outside. She recently joined a swim team and competed in her first meet, where I was likely the only mom with tears under my sunglasses! I was overwhelmed with joy and gratitude—two years ago, our little girl couldn't even raise her arms above her head, but today she could swim the butterfly stroke across an Olympic-size pool.

When I started working again, I realized that when I write about healthcare, I have a greater sense of purpose and depth of understanding. When I write an article about surgery and general anesthesia, it's no longer an abstract concept but an experience seared into my memory.

I know that the patient experience begins long before you meet the doctor. I know that sometimes even parking your car can become a big part of that experience—especially when you have to park at a distance with a cranky toddler in a stroller, and a child hobbling in pain. I understand the fear that patients may feel, and I appreciate the role of the oft-forgotten caregiver.

This isn't the childhood we envisioned for our daughter, but then I try to remember the quote: "Life isn't about waiting for the storms to pass, it's about learning to dance in the rain." When friends threw a party, with a band, in their

“When I write about healthcare, I have a greater sense of purpose and depth of understanding.”

backyard, Ansley's ankles were hurting and her arm was sore from having just finished a 3-day IV treatment. Yet she danced all night long with her daddy, wearing her favorite red cowboy boots with ankle braces underneath.

Watching her, I thought to myself, "She's happy. And it's time for me to be happy again, too."

And I am.

Erin Moriarty Wade, is a freelance writer whose writing focuses on topics in healthcare. As a reporter, she has covered everything from the AIDS epidemic in Southeast Asia to hospital competition in Atlanta. At present she mostly does content writing for healthcare organizations. Find her on Twitter at [@EMoriartyWade](https://twitter.com/EMoriartyWade).

Stories Matter: Why You Should Embed Patient Stories at the Heart of What You Do

By Marie Ennis-O'Connor

“

Stories are the most important thing in the world. Without stories, we wouldn't be human beings at all.” - Philip Pullman

There is something universal that occurs in the brain when it processes a story. Story engenders empathy. It's the best tool we have for putting ourselves in another's shoes. When we learn someone's story, we feel connected to them. Neuroeconomist Paul Zak conducted research which showed that reading humanistic stories actually changes what is in our blood streams. He took blood samples of subjects before and after reading a story about a father and his terminally ill son and found that after reading, the subjects' blood levels contained an increase of two chemicals—cortisol, which focusses our attention, and oxytocin, the human bonding or empathy chemical.

Zak's research suggests we can use story to build a bridge of empathy and compassion in healthcare. To enter into an experience which often lives outside our own understanding requires finding a point of entry. Through story we begin to discover the commonalities we share as humans. To quote Jay Baruch M.D., “Story becomes the ground that patients and healthcare professionals travel together.”



Seeing “this patient”

There is no such thing as a one-size-fits-all patient—yet the health care industry has a tendency to think otherwise. Mayo Clinic endocrinologist and Professor of Medicine, Victor M. Montori, M.D., has referred to seeing “this patient, not patients like this.” In order to see this patient we need to see beyond the one-size-fits-all label. In strictly limiting its focus to narrow biological terms, medicine has largely overlooked the personal, individualized experiences of illness and has lost sight of the person with the illness. Patient narratives act as a foil against stereotyping and reductionist thinking, allowing us to see that a patient isn't a disease with a body attached, but a life into which an illness has intruded.

The Experts By Experience series, a collaboration by Mayo Clinic and Inspire, offers a window into the human heart of medicine. Narrating the experience from the receivers' point of view, the stories illuminate lives interrupted by medical crises. They point to aspects of care and cure beyond the standard medical model of disease. Within these stories



you will find a great diversity of expertise and richness of experience than any bio-medical narrative of disease will teach you. To quote research professor Dr. Brené Brown, “Stories are just data with soul.”

Embedding stories at the heart of your work

We call storytelling, the art of storytelling, but listening is an art too. In her TED talk, Sayantani DasGupta, M.D., says listening to another person is an act of profound humanity. Listening shouldn't be a passive experience—it is a choice we make to pay attention with purpose, listening from a deep, receptive and caring place in ourselves. As professionals working in health care communications, a fruitful place to begin work on improving patient communication is with the quality of our listening. Here are some things we can do to listen more deeply and embed patient stories at the heart of our work.

- Immerse yourself in patient and caregiver stories. They are the fabric and context of our work, allowing us to develop empathy and an appreciation for the narrative complexity of the lives of the patients and families we serve.
- Recognize that patient stories are teachable moments, providing you with rich insights into the embodied experience of illness. Listen for what lies “between the lines.”
- Seek out a wide diversity of experience. Pay particular attention to those stories that are outside your present sphere of knowledge and understanding. Allow them to challenge any prejudgments you may carry. Develop an ear for how a patient speaks so you can communicate with them in ways that will resonate best with patients and their families. Listen to the words, tone and syntax they use to describe the experience of being ill and seeking medical care.

“Listening shouldn't be a passive experience.”

Replicate that language and tone in your own communication with patients.

- Finally, always be mindful that when someone shares a personal story, they are sharing a piece of themselves. Patient stories are not a commodity. They are more than words on a page. Behind every story is a human with a deeply personal experience, that we are privileged to share.

As authentic human experiences, stories echo our humanness. They have the power to connect across differences and unite us through a shared sense of purpose and passion for the work we do. When you allow stories to touch your hearts and minds, you expand your horizons—you walk along the same path with the patient. In the words of Jay Baruch, let story become the ground we walk together.

Marie Ennis-O'Connor is a digital communications strategist and internationally recognized speaker and writer on emerging trends in digital health and participatory medicine. She serves on the external advisory board of the [Mayo Clinic Center Social Media Network](#), and on the board of trustees for the [Patient Empowerment Foundation](#), a network of people, foundations, organizations and medical institutions dedicated to empowering patients worldwide. Find her on Twitter at [@JBBC](#).

Narrative in Health Care: Curiosity, Context, Collaboration

By Pam Ressler

“ We tell ourselves stories in order to live.” – Joan Didion



As our tools of medicine and technology have exponentially increased to include electronic medical records, codes for specific illnesses, and metrics of quality that are often procedure-based, what have we gained and what have we lost? We have gained miraculous biomedical methods for treatment of disease and trauma and an ability to increase the lifespan for many. But, I believe we have lost the context of health and illness that were woven together from the stories of the experience of living with chronic illness as well as the context of witnessing and the human experience of suffering and healing.

If we, as health care practitioners, don't have insight into the stories that the patient brings and shares, the care we recommend may be clinically correct, but most likely will not be appropriate for the individual.

Stories help us gain context. In health care, we use metrics to determine quality, yet context is something that our current metrics do not include. Without context, we do not have a complete picture of meaning, understanding, values, strengths, and challenges that the experience of illness has on an individual.

Eliciting a narrative is a tool that can be taught and practiced in health care, just as we train our practitioners in the use of biomedical tools. Weiner and Schwartz have described the strategic use of narrative process as “contextualizing care.” Their research suggests inclusion of narratives within health care encounters not only provides more appropriate care, but also delivers lower health care costs as a result.

In the Pain Research, Education and Policy Program at Tufts University School of Medicine (where I am a faculty member), a required skill for all our graduate students is learning to elicit a pain narrative as part of a patient encounter. What both the practitioner and patient gain in this collaboration is greater than what can be achieved by only using quantitative pain assessment tools. The pain narrative in the program is derived from the explanatory model (Kleinman) and allows for open-ended responses that elicit a glimpse into the individual's pain and suffering that isn't possible in a 1-10 numerical response.



Too often, fear creates resistance. There's the fear of practitioners worrying that eliciting narratives will take an inordinate amount of time, and they will be overwhelmed with what to "do" with the information in the patient stories. There's the fear among patients that their stories will not be respected, seen as relevant or heard with compassion. If both practitioner and patient understand that this process may result in better, more cost-effective, targeted, relationship-centered care, these fears dissipate.

So, how might we begin to prioritize the importance of patient stories to health care? Start by incorporating the three C's—*curiosity, context, collaboration*—as a means of allowing a narrative to unfold.

Practitioners can try prompts such as, "Tell me what you think I need to know about you," or "What should I have asked but didn't," and then simply listen, without note-taking or data entry. Be curious. Be respectful. By listening, you are being invited into the story.

For patients, try to add context during your clinical visit, by offering a bit of insight into you as a person, not focused entirely on your disease. This helps to position yourself as a collaborator of care versus a passive recipient, allowing your practitioner to understand what matters to you everyday. Here are some examples:

"It's really important to me to be able to cook for my family."

"I have always been very active, running 5K races until a few years ago, and it's challenging not to be able to do that."

We can all work with the 3 C's—curiosity, context, and collaboration—by expanding our shared experience with the larger world. Co-

Trust can allow a patient's narrative to unfold

design and co-creation of projects between patient-focused organizations and health care institutions promote, amplify, and prioritize the social elements of stories and narratives. Online communities provide ways in which stories are heard and shared peer to peer. Personal blogs, artistic expressions such as music or visual art allow individuals to attach context and meaning to the human experience to share with others. The social aspect of telling and listening to stories is important to regain or maintain our connection with the world especially in times of illness.

As we explore and nurture the elements of eliciting narratives—curiosity, context, and collaboration—we will begin to understand, with greater clarity, that stories do matter in health care.

Pamela Katz Ressler, MS, RN, HNB-BC is the founder of Stress Resources in Concord, MA, a firm specializing in building resilience for individuals and organizations. Additionally, she is an adjunct clinical assistant professor of Public Health and Community Medicine in the [Pain, Research, Education and Policy program at Tufts University School of Medicine](#). Ms. Ressler's research has included one of the largest studies on patient blogging, *Communicating the Experience of Chronic Pain and Illness through Blogging*. Find her on Twitter at [@pamressler](#).

Message in a Bottle? What Lost Rubber Ducks in the Ocean Can Teach Us About Patient Care

By Dr. Farris Timimi



Over a quarter of a century ago, a toy company placed an order with a manufacturer in China for a shipment of bathtub toys. There were four toys in the “Friendly Floatees” family—red beavers, green frogs, blue turtles and yellow ducks. The container ship carrying the order left Hong Kong in January 1992, en route to Tacoma, WA. On January 29th, during a fierce storm in the North Pacific Ocean, twelve 40-foot containers—two of which held 29,000 Friendly Floatees—washed overboard.

Shortly after the containers went in, they broke apart, and the Friendly Floatees were adrift, floating in the cold waters of the Pacific.

The Friendly Floatees were caught in a large ocean whirl, the Subpolar Gyre, which is a marine gyre roughly the size of Texas in a constant slow spin. Often, debris can be caught in this gyre for up to 50 years, trapped in a large, slow rotation. Fortunately for the fearless Friendly Floatees, they were able to break free of the gyre, and roughly 10 months later, they started to wash up on the shores of North America, initially in Sitka, AK. The vast majority of the Floatees then re-circulated in a massive counter-clockwise loop, a journey taking over

three years, circling from Alaska in a large loop to Japan, then past the initial site where they were washed overboard, then back again to Alaska.

In 2000, eight years after their journey started, Floatees began to pop up on the eastern seaboard, from Maine to Massachusetts. And in 2007, Penny Harris, a retired school teacher, found the first trans-Atlantic Friendly Floatee, a yellow duck, on Devon Beach in the United Kingdom.

This charming tale should have ended at this point, if not for an oceanographer named Curtis Ebbesmeyer. Curtis was an oceanographer, studying the movement of buoys he would drop in the ocean. His mother had heard of the trip that the Floatees had taken, and asked her son, “Isn’t that what you do?” encouraging him to think outside of the box and start collecting careful records of where and when the toys were discovered.



Using this data, meticulously mapping the course and trajectory of each of the Friendly Floatees and their landing sites and dates, he built a current flow model that resulted in the development of OSCURS, the Ocean Surface Current Simulations. OSCURS now allows oceanographers and fisheries to perform daily analyses of ocean currents in the Pacific—it has become the standard for ocean current simulations.

All this, from carefully observing the trajectory of rubber bathtub toys!

My intent here is not to compare bath toys to patients. Instead, I would remind you of the real learning value for physicians in truly listening to the real-life trajectory that patients take. Too often in medicine, we interact with patients at discrete points in their journey, as they move from illness to recovery. As a result, we often do not understand the entirety of that path, seeing isolated snapshots in a much more complex story. Only by viewing and sharing in the breadth of the patients, each traveling their own path, can we begin to understand the challenges they face and the learnings they make.

From a practical standpoint, healthcare professionals should view social media as a population-based tool that adds a one-to-many channel to the one-to-one engagement that occurs in the exam room. Consider exploring an online disease-focused community, or a Twitter chat, that is relevant to your practice, to better understand a patient's challenges and insights. Sharing content is best viewed not as a broadcast channel, but rather, as an opportunity to create or curate valuable content to patients in a platform that allows this content to be shared regardless of time or space confines. By doing so, you extend that conversation to those who may not be able to participate.

“ Only by viewing and sharing in the breadth of the patients, each traveling their own path, can we begin to understand the challenges they face and the learnings they make.

Fundamentally, remember to focus on the tapestry that is woven by the patient stories, for there is more to be learned in listening than in talking.

Dr. Farris Timimi, M.D. is a cardiologist at Mayo Clinic in Rochester, Minnesota. Dr. Timimi serves as Program Director for the Advanced Heart Failure Transplant Cardiology fellowship program, and as enterprise medical director for the Mayo Clinic Center for Social Media, with focus on the application of health care social media to domains of medical research, education and medical practice. Find him on Twitter at [@FarrisTimimi](https://twitter.com/FarrisTimimi).