Experts by Experience
A compilation of patients’ stories

A special report by Inspire, developed in cooperation
with the Stanford University School of Medicine

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Introduction
Welcome to Experts by Experience--A compilation of patients’ stories., a special report by Inspire.

In early 2012, Inspire partnered with the Stanford University School of Medicine to provide a monthly column for the Scope medical blog. This report, Experts by Experience, is made up of a year’s worth of columns from patients of all types and backgrounds. An underpinning of all the columns is the desire by patients for their doctors to truly hear them, and consider them a partner in the care process. Many patients want to share their stories, to help themselves and others. As Laura Haywood-Cory, a woman with a rare heart disorder, said, “As patients, we need to not expect perfection from our doctors until we achieve it in ourselves. And doctors need to give themselves permission to not know everything and to not feel threatened by empowered, educated patients.”

We at Inspire are grateful to Scope editor Michelle Brandt, associate director of digital communications and media relations at Stanford University School of Medicine, and to Aanand Naik, MD, of the Michael E. DeBakey Veterans Affairs Medical Center., who wrote the foreword for this report. We appreciate the innovative work of Stanford physician and Medicine X conference organizer Larry Chu, MD, whose annual event focuses on the use of social media and information technology to empower patients to be active participants in their own care.

Special thanks to the Inspire members who agreed to share their stories through the Scope blog. Lastly, we are grateful to all our members in the Inspire community, who, through their stories, are working to improve their own health or that of a loved one.

Together we’re better.

Brian Loew
Co-founder and CEO
Inspire
Foreword: A clarion call for patient-centered care from the patient perspective
Aanand D. Naik, MD

Each of the columns in this compilation is a first-person narrative of the patient perspective on healthcare, illness, and personal growth. The writers are inspiring in their honesty, strength, struggle, and perseverance. As a medical geriatrician and health services researcher, I am also struck by several recurring themes that represent clear criticisms of modern health care and the contemporary state of the doctor-patient relationship.

I am an advocate of “patient-centeredness,” an important and distinct dimension of health care quality. The Institute of Medicine describes patient-centered care as care that is respectful of and responsive to individual patient preferences and needs and consistent with patients’ values. This high-brow definition can be simplified into two basic elements: attention to the patient’s experience of care and aligning care to patients’ elicited goals. A particular elegance of these columns is how each personal story illustrates specific details of how to better attend to the patient experience and to how clinicians can elicit and align care to their patient’s goals.

Attention to the patient experience is principally about person (not disease) centered communication. Mark Nelson’s story, “No day on the beach,” eloquently describes that person-centered communication involves spending time, showing respect, explaining things simply, listening and encouraging questions. Mark’s story also describes the importance of setting expectations about what to expect, especially for
chronic conditions, and how to integrate aspects of treatment into a patient’s daily routines.

Heather Pierce’s story, “Zebras with different stripes,” describes a wonderful exchange with a physician who clearly understands person (not disease) centered communication. Her doctor stated, “I see here you have Ehlers-Danlos Syndrome. How does it feature itself in you?” Pierce writes of how happy she was when she said, “I wanted to hug him . . .I had found someone who would treat me individually.”

Leanna Scaglione’s “Defying a diagnosis and continuing to dance,” describes the anxiety and frustration associated with having to move from a physician who understands the patient experience to one who doesn’t. Stan Hardin’s, “Looking for comfort during a less-than-comfortable diagnosis,” relates another aspect of the patient experience. Stan describes the importance of having a physician who offers choices, helps patients deal with the emotional and psychological aspects of illness, and considers how treatments impact those person centered aspects of care.

Aligning care to patients’ goals is the other important element of patient-centeredness. Several stories in this collection describe important details of how this can be effectively done in medical encounters. In several of the stories involving rare or missed diagnoses, such as Becky Dennis’s “An encephalitis journey,” there are descriptions of how the illness impacted social and occupational roles. The fact that these symptoms had no clear medical diagnosis exacerbated the functional and existential impact of real but unexplained symptoms. Laura Haywood-Cory’s “Dr. Google: threat or menace?” eloquently describes the social as well as individual significance of illness and the need for finding and being a part of a community that is affected by
similar symptoms and conditions.

Patient-centeredness means that physicians and patients are cognizant of the social, occupational, and psychological impact of treatments and health services on one’s roles and responsibilities as well as their biomedical consequences.

Patient-centered care expects that patients and their clinicians will elicit, explore, and plan for the full spectrum of patients’ goals and expectations for their health and life.

This collection of columns underscores the importance of giving voice to patients’ narratives of health care and illness. It is through these narratives that our health care system can continue on its journey down the road to patient-centeredness.

Aanand D. Naik, MD is an investigator and chief of the education and training core at the Houston Health Services Research Center of Excellence at the Michael E. DeBakey Veterans Administration Health System and Baylor College of Medicine. His research focuses on the conceptualization of patient-centeredness as a distinct dimension of health care quality.
An encephalitis journey:
A dozen doctors and 2.5 years

Becky Dennis

In February 2008, I traveled from the U.S. to Southeast Asia for business meetings. Five days later, I delivered a presentation, feeling confident and full of life. Two hours later, fatigue stung me, nearly paralyzing my speech. My vision blurred. My lips and limbs tingled, then fell numb. A company car raced me to the emergency room. Walking required so much effort that my body yielded to a wheelchair.

My mind raced for answers. Did I not acclimate? Did I forget a medication? Can I simply not keep the pace of my older colleagues?

Doctors’ and nurses’ words bounced in my head. I couldn’t remember how to talk. Fog settled in my brain, and my fear intensified. A cardiologist ran tests: borderline EKG. Within six hours, some faculties returned. Without conclusive tests, the doctor discharged me, citing fatigue and stress as the cause for my illness.

In the U.S. two weeks later, a neurologist diagnosed me for stroke. A series of MRIs and other tests returned insufficient evidence. He dismissed me, recommending psychotherapy. He offered no explanation for the constant headaches, tingling sensations, slurred speech, and short-term memory loss.

As a senior vice president for a publicly traded company, and someone who had always been an extremely independent person, I found myself struggling to retain the life I knew. Poor concentration plagued my work, and I needed five naps a day. Fatigue overwhelmed me to an extreme. I’d finish a conference call, and
then my head would collapse on my desk in my home office because I was unable to take just 20 steps to my bedroom. My sister would call to see how I was doing, and she’d ask, “Did I wake you up?” at two o’clock in the afternoon. She’d say, “You were asleep the last time I called you. You’re going to get fired.”

Because of vision issues, I couldn’t even drive – let alone fly. My husband had to take me to business meetings, and I was no longer able to navigate the complexities of globetrotting. I felt helpless.

In the absence of a fitting diagnosis and the suggestion that stress caused my neurological phenomena, I fought to conceal my illness. I knew I wasn’t crazy. I didn’t cause these symptoms. Fear of another episode distracted me, making me feel like a time bomb. Months passed. Some doctors still thought stroke. Some thought complicated migraine. Some sided with the stress factor. The symptoms lingered. After 2.5 years and 12 doctors, I pushed for answers.

In May 2010, I visited Massachusetts General Hospital, presenting notes and tests from the previous 30 months to a neurologist. He examined each symptom, including loss of taste and smell, aphasia, and loss of peripheral vision. He concluded, “This is clearly encephalitis, likely from a mosquito bite.”

In that moment, I felt vindicated. Validated. My spirits lifted, knowing that this doctor looked closely enough to understand me. Such complex symptoms were not, could not, be stress.
I learned that encephalitis is acute inflammation of the brain, typically caused by a viral infection and resulting in acquired brain injury. (Familiar forms of encephalitis include the West Nile virus and herpes simplex encephalitis.) Compared to meningitis, which is swelling in the outer lining of the brain, encephalitis is inflammation of the brain itself and has a high mortality rate. I discovered that the mortality rate for the kind of encephalitis I contracted, Japanese Encephalitis, has a mortality rate of one in three. An alarming statistic.

Recovery is a long process for most patients, requiring rest to give the brain the opportunity to restore function. Rehabilitation for this illness is similar to stroke recovery, such as speech therapy, physical therapy, psychotherapy and cognitive therapy. I was in for a long journey.

Just a few weeks after getting my diagnosis, I started writing my book about encephalitis and my experience. I wanted people to understand that the cruelty of this disease is its silence: Though those of us who have survived appear to be functioning at 100 percent, the disease locks away our memories and prevents us from concentrating on what our friends and families are sharing with us. It is critical that swift diagnoses be made, and I consider it my mission in life to educate and bring about awareness in hopes of preventing others from going down the same path that I did.

Becky Dennis, of Plano, TX, is a board member of Encephalitis Global, Inc., an international patient advocacy organization, and is the author of a 2012 book, “Brain Wreck,” about her encephalitis journey. Dennis worked with Inspire to create an online report on the impact of encephalitis on patients and their families. The report can be downloaded here.
Dr. Google: Threat or menace?
Laura Haywood-Cory

Three years ago, when I was 40 years old, I had a heart attack, caused by a rare thing called a Spontaneous Coronary Artery Dissection, or SCAD.

Arteries are constructed in layers, and a dissection is when the inner layer tears away from the middle later. The torn flap of artery creates a blockage in blood flow to the heart, which can cause a heart attack, cardiac arrest, or death.

After two cardiac catheterizations, six stents, and a week in the hospital, I was sent home with precious little information other than: “SCADs are rare. You’re lucky you survived.”

I’m grateful to the doctors, cath lab staff and everyone at the hospital who took good care of me. I know they can’t possibly know about every long-tail edge case that walks in their doors. But the first two weeks home from the hospital were terrifying. I would keep myself awake for as long as I possibly could, because I was afraid that if I went to sleep, I might never wake up again. That’s a scared and lonely place to be at 3 AM.

As a child of the digital age, I went searching for answers online. As part of my research I came across an online support community, where I connected with other women who’d not only had a SCAD but were several years down the road of recovery and were doing well. These women have been a real lifeline for me, and if not for them, I’d still be lonely, scared, and without any real information on my condition.
Recently I was reading KevinMD and found a post of interest. In the piece, called “Saving patients from Internet health information,” Stewart Segal, MD, expresses his frustration with patients who self-diagnose via Google and then decide, unilaterally, on different courses of treatment than what he has prescribed for them.

As a patient with a rare condition that most cardiologists have never encountered, I and others like me have had to become our own experts. And since our numbers are small, we aren’t able to gather for support in person; we do it online.

It seems to me that the answer isn’t to discourage people from seeking medical information from “Dr. Google,” but rather to teach people, starting in school, some critical thinking skills.

Laura Haywood-Cory lives in Durham, NC. In 2012 she received a Woman’s Day Red Dress Award for her role in a Mayo Clinic study on the feasibility of recruiting patients through the use of social media.
Clinical trials: My next good chance
Linnea Duff

On April 5, 2012, I quietly noted the seventh anniversary of the day my world turned upside down. For two years a persistent cough and shortness of breath had been attributed to adult onset asthma. It was only when I developed pneumonia that a chest CT scan was ordered, revealing a 5-cm mass on my left lung. A biopsy confirmed the unthinkable; I had an uncommon variety of non small cell lung cancer.

I was 45 years old and had never smoked. The only thing I knew about my diagnosis was that the overall five-year survival rate for lung cancer was only 15 percent. Determined to beat those odds, we transferred my care to Massachusetts General Hospital, where we hoped I’d have access to the most current research in the treatment of lung cancer.

Despite removal of the entire lower lobe of my left lung as well as adjuvant chemotherapy, my cancer recurred almost immediately. Three years after the initial diagnosis my health began to decline rapidly. Another therapy proved useless and my cancer was now deemed terminal. The situation seemed hopeless when a new biopsy revealed that I was positive for a mutation of the ALK gene. Given the chance to enroll in a phase I clinical trial for an experimental therapy that targeted the newly identified ALK mutation, I jumped at the chance.

Clinical trials, which remain under-referred as well as underutilized, have become my personal lifeline. I no longer view clinical trials as a last resort, but rather as my next good chance.
And then an amazing thing happened. While I had hoped the experimental drug (crizotinib) would extend my life for several months, I ultimately spent almost three years on the trial. Six months ago, I entered my second phase I clinical trial for yet another ALK inhibitor (LDK 378).

Clinical trials, which remain under-referred as well as underutilized (enrollment of cancer patients hovers around 5 percent), have become my personal lifeline. I no longer view clinical trials as a last resort, but rather as my next good chance.

I am fortunate to have been able to participate in these trials at the same hospital where I receive my care, but I know patients who travel great distances to gain access to experimental therapies.

These patients generally share my perspective; we are aware of the risks and understand that not every clinical trial will be effective in treating our individual cancers. And yet, we embrace the opportunity to enroll. Perhaps our quality of life will be enhanced and our lives extended.

No matter the outcome, we’ve been given the opportunity for not just another avenue of treatment, but to do something meaningful. By participating in a clinical trial, we are paving the way for other patients; the experimental therapies of today may become the gold standards of tomorrow.

Linnea Duff, of Amherst, NH, is a married mother of three who has been battling NSCLC (stage IV) for over seven years. She blogs at life and breath: outliving lung cancer.
The Beast cut in on my song: Living with coronary microvascular dysfunction

Annette Pompa

In 2010, I was a 40-year-old active mom of two, and an art teacher/artist who loved to run and lead a healthy lifestyle. That year, the Beast rudely cut in.

The “Beast” is a not-so-affectionate name many of us with coronary microvascular dysfunction give to MVD. In MVD, it is thought, the microvasculature lacks enough nitric oxide and constricts. It doesn’t adequately feed the heart muscle, causing angina and other symptoms.

For me, my new life with MVD began after a run, when I felt extreme fatigue. Three days later, the fatigue, pain, heaviness in my chest and shortness of breath were overwhelming. I couldn’t even read to my kids. This began blood tests and visits to the ER, my GP and specialty doctors. I had stellar blood work. Symptoms kept pointing back to my heart. Except for a little ischemia on a nuclear stress test, I should be healthy. My first cardiologist dismissed it!

It was frustrating to be labeled not a cardiac patient when I presented like one. I was told, “You’ll be fine! Exercise!” Really? I was debilitated with angina, shortness of breath and fatigue. I could not walk, let alone run, without consequences. I had to quit teaching. I was sleeping or managing too much angina. If my life were a dance, the music nearly stopped!

Months dragged by. I researched and found similar stories of women who had been misdiagnosed – some for years. Unfortunately, at times, women are compared to male cardiac patients. It turns out MVD is often invisible in typical cardiac testing. I found a cardiologist involved in the Women and Ischemia Syndrome...
Evaluation (WISE) study, and it was confirmed. I was diagnosed five months after this began. No cure, but he offered hope in managing the symptoms! He was in my corner until I found a local cardiologist who would work with me.

The tempo of my life changed. Treatment began. I had an increase in energy but pain persisted. I need nitroglycerin for daily angina. Nitrates help constricted micro vessels dilate. I began long-lasting nitrates and use sublingual nitro at will for break through pain. Life began getting better. “Better” was not returning to work. But I no longer slept all day, and had some relief from angina.

The Beast still cuts in. So much is not understood. But now I feel more control.

My song is slower, but it’s better than the wallflower the Beast had reduced me to!

We need more research into MVD. Each patient varies in severity. No one knows why. Some have daily bouts of it, others weekly or monthly. It is serious and often debilitating. There are doctors who believe this is clear-cut and we are all just dealing with a nuisance. Physicians need to understand MVD better and quickly treat our angina symptoms even as they do tests.

Patients also need to be their own best advocate. We must act on these symptoms regardless of diagnostics that have difficulty showing MVD. Patients need to be helped in a timely manner to limit the potential heart cell damage and increase our quality of life – our song.

Annette Pompa of Catasauqua, PA, blogs on microvascular dysfunction and posts medical info on the Coronary Microvascular Disease page on Facebook.
Expert by experience: Living with, and teaching about, short bowel syndrome

Andrew Jablonski

I am 26 years old and have lived with short bowel syndrome, a rare intestinal disorder, my entire life. When it comes to this disease, I’m an expert by experience.

Short bowel syndrome (SBS), which affects about 15,000-30,000 people in the United States, is the result of a congenital defect (NEC, gastroschisis, and volvulus, to name a few) or trauma. Crohn’s disease is also a leading cause of SBS.

SBS is a condition that reshapes the way you live. There are multiple things a patient has to become accountable for, including self-managing the condition, keeping on top of medications, and making frequent visits to the doctor. In many cases, SBS patients face frequent diagnostic procedures or surgeries, or both. To manage the disorder, SBS patients have to make major changes to their dietary needs to help supplement what they do not get through oral feedings, often through TPN and enteral feedings. Dietary management is one of the biggest challenges of the disease.

Many things in your life change when you have a chronic condition like SBS – some good, some bad. One downside is that there’s always some sort of “fear factor” involved, with the patient wondering what could happen after one infection too many, and worrying about the multiple things that could go wrong
from undergoing surgeries and procedures. On the plus side, living with a chronic condition prompts patients to learn techniques that allow them to live a productive life and to learn how to effectively communicate with their healthcare provider.

Many SBS patients want to study the condition and understand it better, so they can be more efficient with their lives and time. I am one of those people, and being around medicine my entire life was a driving factor to becoming a full-time patient advocate and support resource for other patients like myself.

For the past two years, I’ve attended Digestive Disease Week, a major conference held each May that brings together more than 15,000 gastroenterologists, industry professionals, medical students, and vendors from all over the globe. Also at the conference are some people like myself, who live and breathe SBS every day.

I had many opportunities to talk with physicians at the recent conference, and our conversations usually started with them asking, “Why are you here?” When I explained that I’m an advocate for SBS research and awareness, as well as an SBS patient, their attitudes changed, and they became receptive to me and

Not all physicians I’ve met at conferences have been welcoming, but many have been. And some have gone as far as to tell me that I’ve taught them more about my disease then they ever knew.
my mission at the conference. Many agreed that there’s a need for SBS to become better known in the GI community and that there’s no real support for patients and caregivers. Hearing those sentiments confirmed that I’m on the right path with the foundation I started two years ago.

Not all physicians I’ve met at conferences have been welcoming, but many have been. And some have gone as far as to tell me that I’ve taught them more about my disease then they ever knew. Most physicians study a disease process a few times in medical school and then will only see a case or two in their careers, one GI told me, unless they really specialize in a particular condition. Hearing that I provided these doctors with new insights about this rare disease was empowering to me.

As a patient advocate, I know that it’s because of healthcare providers that patients like me continue to thrive. But more medical professionals can benefit from listening more to their patients, and doctors can learn from the experts who come into their offices and hospitals every day.

Andrew “Andy” Jablonski, of Lincoln, Neb., founded the Short Bowel Syndrome Foundation in December 2010 as a resource for SBS patients and their families.
Zebras with different stripes: One patient’s story

Heather Pierce

Though I’ve been impacted by Ehlers-Danlos Syndrome (EDS) ever since I was a child, I didn’t first hear of this genetic connective tissue disorder until I was in my 30s. A serendipitous meeting with a geneticist changed my fate.

In my nervous introduction, I promised the new doctor that I was not a hypochondriac, but really did have a funky body. Her curiosity piqued, she smiled a little and responded, “Try me!” After hearing my symptoms, she had her own questions, which initially seemed random, then slowly started to connect the dots of my life. Who else in my family was like me? What were my pregnancies like? What injuries have I had, and did I have any problems healing? She felt my skin and started bending my joints. Then she started talking about Ehlers-Danlos Syndrome.

For the first time I made perfect sense to a doctor, and it blew my mind!

Lack of awareness about EDS and stories of it taking years to get a correct diagnosis have led us patients to call ourselves “medical zebras.” For me, my hoof beats were not those of the horses that doctors are asked to think of first; doctors who saw me would mention multiple sclerosis, lupus, and irritable bowel syndrome before settling on fibromyalgia. While I spent years seeing specialists and undergoing tests, EDS was not considered by anyone.
After my misdiagnosis of fibromyalgia, I spent the next 14 years damaging my body believing my pain was a false indication of an otherwise functioning, if neurotic, body. Well-intentioned doctors, seeing the horses they were supposed to look for, used my misdiagnosis as a dumping ground for my growing problems.

Eventually, the compiling effects of injuries, increasing dysautonomia, pain and joint weakness created a virtual checklist for a doctor educated in EDS.

EDS is a frustrating diagnosis – the disease exhibits itself differently in each person and has no cure or treatment outside of supportive interventions.

Some people are mildly affected while others find themselves unable to function outside their beds. Genetic testing is not fully developed for some of the six types. And current imaging techniques don’t show the severity of the impacts on the body, especially the pain, which is both chronic and acute.

But looking for answers with my great team of current doctors, researching the ever-growing amount of information, and connecting with others with EDS keeps bringing home to me the fact that even medical zebras have different stripe patterns. One patient may be struggling with mobility issues from sudden...
dislocations of knees and hips, while another experiences more subtle impairment, as a joint slowly slides out with an activity such as walking.

One person’s body may react to the hypermobility by locking in spasms, while another can do nothing effective to tighten up a loose joint. Someone may have severe gastric issues while another struggles with vision. The possible effects of faulty connective tissue are endless.

Last spring, I met with my new primary care doctor for the first time. Our discussion began with him reacting to my diagnosis by saying, “I see here you have EDS. How does it feature itself in you?” I wanted to hug him! It was so wonderful to feel like I had found someone who would treat me individually.

As EDS patients, our experiences are so different that all theories, symptoms and treatments won’t apply to all of us. But it’s important for people to understand that this doesn’t make EDS less legitimate or our experiences in it less valid. After all, zebras make hoof beats too!

*Heather Pierce, of Baltimore, MD, is a married mother of two who co-leads an Ehlers-Danlos support group and is a volunteer for EDS awareness and education.*
Doctors: Please have “ears that hear”

Judy Peterson

Several years ago we moved back to the Midwest, and I needed to find a family physician. I opted for a female doctor, hoping that as a woman she might be more tuned to my aging female body and to its potential health problems. Potential, I say, because I thought I was in good health.

I liked my new doctor and enjoyed my annual physicals and other visits. But looking back, I wish she would have listened more closely to my seemingly minor complaints. I may have been ignorant about the subtle and near-silent symptoms of ovarian cancer, including rib pain and the frequent need to urinate, day and night, but my doctor should have known. I expected her to know.

It was in 2007 when I first mentioned rib pain to my doctor. I told her I couldn’t sleep on my right side. Six months later I mentioned it again, and in late 2008 I once more mentioned the nagging discomfort. During that visit my doctor did a two-second rectovaginal pelvic examination and, as part of my physical, a full blood work-up. The results were still at the lab so before I left I asked her to send me a print-out.
Several days later my blood results arrived in the mail. Three pages. At the top of the first page my doctor had written, “Looks great!” endorsed by an inked smiley face. I casually scanned down the first page. Everything looked normal. But when I got to the third page I noticed my alkaline phosphatase reading was abnormally high, and I did what any normal person does these days: I Googled. Possibilities included problems with the gall bladder or liver and that dastardly word “cancer.”

Naturally, I opted to think it was a gall bladder problem and asked for an ultrasound, which showed a large gallstone that I went in to get removed.

My gall bladder surgeon was the one to give me the bad news. As I came out from under the anesthesia, his face swirled in the white light above me while he told me he had found cancer in my abdomen and on my liver. I remember distinctly the photos he showed me. Still under the influence of anesthesia, I replied quietly, “That is not good news.”

Fortunately for me, my surgeon referred me to a Gyno/Onc who debulked me, removed 95 percent of the cancer, tied my intestines into little “animal balloons” (I jest only slightly), returned them to my ab cavity and put me back together with 43 metal staples. I had just endured the “mother of all surgeries.” It was a brutal surgery but without it I would be long dead. The official diagnosis was ovarian cancer (stage III-C), and chemo followed. And followed. And followed.

Three and a half years later, I’m on my 5th chemo regimen. All things considered I’m doing fairly well: I lead an active life, do some volunteer work, take care of my home. I’m grateful to be alive. But I can’t help but
I can’t help but think that if my doctor had listened more closely, more sharply, with “ears that hear,” to my ongoing complaints about rib pain, or if she had provided me with a simple informational brochure so I would have been more knowledgeable, perhaps I would have been diagnosed long before Stage III-C.

Every woman knows about breast cancer. But very few know about the symptoms or diagnostic tests involved with ovarian cancer – which could be why most of us are diagnosed late in the game, when statistics for survival are grim.

Awareness is the most important piece of diagnosis – awareness by both the medical professional and the patient – and so I ask doctors to educate themselves and their patients about this deadly cancer.

Judy Peterson, of Onawa, IA, is enjoying her retirement years with her husband, children and grandchildren. She blogs about a variety of topics, including her walk with ovarian cancer, at Wanna Walk Along?
No day on the beach: A colon cancer survivor’s story

Mark Nelson

My family and I have always enjoyed the beach, and our goal this past summer was to spend time on one, soaking up the sun and swimming in the ocean. I had a little challenge, though: I’m a one-year colon cancer survivor with a permanent colostomy and a small hernia alongside my stomach. My stomach bulge is bigger than the average person’s, and that’s something that can’t be hidden on a beach.

It was easy to think when planning our vacation that I would have no problem with taking my shirt off and enjoying the sun like everyone else. But I found that as soon as I removed my shirt, people on the beach stared at me and the black tube top I wear to try to conceal my bag and stoma. I was very uncomfortable and felt like a freak.

I’m a cancer survivor. I’ve been through so much. Even so, I wasn’t prepared to feel that way that day. I wish somehow I had been more prepared.

We were never actually told by a doctor I had cancer, though: We found out when we received a phone call from the surgeon’s secretary to schedule an appointment with him.

In fact, I wish I had been better prepared for much of my cancer journey.
I was diagnosed with colon cancer in March 2011. We were never actually told by a doctor I had cancer, though: We found out when we received a phone call from the surgeon’s secretary to schedule an appointment with him. She introduced herself as being with the colon cancer department, and when we heard that we knew this was a far graver issue than anyone had told us.

We went to visit our surgeon. He did a finger rectal exam, and it took him ten seconds to tell me I needed surgery and was going to end up with a stoma and a permanent bag. He kept saying that I was young and that everything would be okay. Well, having a bag and a permanent stoma did not feel okay to me. My life was about to be changed permanently, and I barely had time to process it all.

I had my surgery three months later. After surgery, I had a bag on and a catheter, and I came across a nurse who made an insensitive comment about my stoma. She and many of the other doctors and nurses I came across educated me fairly well about my disease and what was happening to me, but they were often blunt and to-the-point when they spoke with us. I questioned whether they had any concern about my mental well-being, and I wished for someone to ask my wife and I how we were handling all the new information and to give me an opportunity to talk about how I felt.
I was concerned that this disease and its aftermath would be changing not only my life but also my families’ lives. I felt out of sorts, confused, not in control – kind of the way I felt at the beach.

I wound up doing four months of chemotherapy after eight weeks of recovering from surgery. Nobody warned me I would feel like I was on my death bed while undergoing chemo, but I did. I had nine treatments, I lost 45 pounds, and my wife and I didn’t know if I was going to make it. We were both scared: Scared that I might not get through this, scared that my cancer might come back after the treatments, and scared about what our life might be like.

We knew we had to fight to get myself back on track, so we set a goal of traveling to see our kids and to go to the ocean. When we heard I was cancer-free one year out from surgery and chemo, we booked our trip.

And back to the beach: Just as I felt unprepared and not totally supported during my diagnosis and treatment, I hadn’t been prepared for feeling so self-conscious with my shirt off in public. But standing in the sand that summer day, I knew I had to be strong enough to get through it – just as I got through the cancer.

And so, I went from thinking that everyone was looking at me and feeling sorry for me or wondering why the heck I had that stomach bulge and was wearing that weird sleeve to accepting that I’m a colon cancer survivor. And feeling proud of it.

Mark Nelson and his wife live in a small rural town in Northwestern Wisconsin. Mark is a high-school math teacher as well as an entrepreneur. More on Mark’s colon cancer journey can be found on his blog.
From frustration to foundation: 
Embracing a diagnosis of celiac disease

Alice Bast

The day I was diagnosed with celiac disease was the best day of my life.

People always react with surprise when I tell them that. They ask how I can consider being diagnosed with an autoimmune digestive disease such a positive milestone. And I tell them it's because that's the day I got my life back.

In hindsight, I believe a vacation to Mexico played a role in triggering the disease. You see, celiac is a genetic condition, so you have to have a genetic susceptibility in order to develop the disease. But there's something else needed to trigger the onset: an environmental factor, usually some type of emotional or physical stress. There's little known about it, but in my case, I believe a parasite that I caught on vacation was my trigger. I was treated, but after that, things were never the same.

My husband and I were starting a family, and my oldest daughter was born perfectly healthy after a normal pregnancy. My second pregnancy, though, was nothing like the first. Early on, severe fatigue set in. I was constantly weak and rarely got enough sleep, as severe diarrhea, joint pain and migraines kept me awake at night. No matter what I did, I lost weight. Two weeks before my due date, I lost my baby.

Over the years, I went on to have multiple miscarriages before finally delivering my youngest daughter, who weighed only 2 pounds. For eight years, I visited an incredible amount of doctors – 22, to be exact. No one
knew what was wrong with me. At 5’9”, I had wilted to a mere 105 pounds. I thought I was dying. My mother died of pancreatic cancer, and I thought I had cancer too, somewhere - but where? When and how would I find it, and would it be caught in time?

It wasn’t until talking to a family friend, a veterinarian, that I realized that what I was eating could be the problem. She mentioned celiac disease and said that animals can have reactions to wheat. Still on my quest for answers, I visited my 23rd doctor. “Here’s my arm,” I remember saying. “Give me the blood test.” Sure enough, the results came back positive for celiac disease. Finally. After eight years of struggling, I had my answer. There’s no cure for celiac, but I was told that by adopting a gluten-free diet and ridding myself of anything derived from wheat, barley, or rye, my health would return and I could live a normal life. And it did. And I did.

But my story doesn’t end with my diagnosis. That’s where it starts.

I enthusiastically accepted my diagnosis and took on the difficult task of eating gluten-free. No more pizza, pasta, bread, soy sauce, cakes… the list goes on. But I was willing to make the switch to reclaim my health. What bothered me the most about my diagnosis was the thought that other people who, like me, don’t represent the “typical” celiac patient (I wasn’t short, I wasn’t a child, I looked fine), were out there suffering and no knowing why. I had lost my babies, and I was determined to prevent the same thing from happening to other women.
The doctor who diagnosed me retired from his practice, so I switched to a new gastroenterologist, Dr. Anthony DiMarino. Together, Dr. DiMarino and I dug into European research studies and became convinced that the untreated celiac had caused my fertility issues. My commitment to spreading celiac awareness grew stronger. I had to get the word out to people in every way I could. And, so, in 2003 the National Foundation for Celiac Awareness (NFCA) was born.

Years later, I’m still as determined as ever to tell everyone about celiac disease. I’ll stop people in the grocery store to talk to them about the gluten-free food in their shopping carts. I’ve traveled all over the country to host events and speak to doctors to tell them about the realities of celiac disease and that it might not appear as they imagine. With an estimated three million Americans living with celiac and 85 percent of them remaining undiagnosed, it’s my duty to tell people about it.

I don’t want other women to experience the heartbreak that comes with losing a baby due to undiagnosed celiac disease. And I don’t want people to spend years questioning why they’re suffering from depression, digestive issues, infertility, migraines, fatigue or even anxiety. There’s an answer, and that answer could be celiac disease.

Alice Bast is widely considered to be an expert on celiac disease and the gluten-free lifestyle. She is the founder and president of the National Foundation for Celiac Awareness, a nonprofit organization dedicated to driving diagnoses of celiac disease and other gluten-related disorders and improving the quality of life for those on a lifelong gluten-free diet.
Broken: A poem about coming to grips with chronic disease

Angelika Byczkowski

Once I was whole. No, better than whole, possibilities strewn at my feet, choices all mine for the making.

Then I got sick, and broken.

Now I struggle to fly with broken wings. Old ambitions and desires irrelevant, coming down to earth with new humility.

Always aiming for superlatives, now grounded with indistinction, my new insignificance frees me to fly from the need to be special.

Now I struggle to run with broken legs. Can’t keep up, can’t catch up, and the world passes by oblivious to my desperate thrashing.

All that’s gained is lost eventually. I jettison years of accumulation, learn how much I can do without, pare life down
to bare essentials, and find
the remaining kernel sufficient,
my load much lightened and easy
to swing over obstacles ahead.

Now I struggle to live with a broken spirit.
This, I think, I cannot do. I
languish, lacking spur of vital impulse,
motivation crippled, desire withered.

Paralyzed by apathy, stubborn
hope insists, after broken wings
and broken legs, after the crash
and pain of loss comes possibility

for something new. Anchorless alone
I drift, restrain my swelling panic
at this formless space all around me,
no purchase to be gained on these

feeble clouds, nothing solid to push
either for or against – I struggle only
with myself. And in this void I must trust,
resist the urge to close, and endure
with broken open heart.

Until she was disabled by the progressive pain and fatigue from Ehlers-Danlos Syndrome, Angelika Byczkowski
was a high-tech IT maven at Apple and Yahoo. She lives in a rustic cabin in the Redwood forests of the Santa Cruz
Mountains with her husband and two dogs.
Defying a diagnosis and continuing to dance

Leanna Scaglione

Five years ago, I was training to become a professional ballerina. Continual pain in my thigh while dancing brought me to an orthopedist who discovered a tumor the size of a melon in my lower spine, and I wound up being diagnosed with Neurofibromatosis Type 2 (NF2). I was 16 years old.

The removal of the tumor caused enough nerve damage in my right leg where I couldn’t stand without my leg collapsing, thus ending my ballet training and my dreams. I was bound to a wheelchair for almost four months and had to re-learn how to walk. At the time of the surgery, it was explained to me that there was a chance I would not be able to dance again.

Now, at 21, I have defied fate by still dancing and re-obtaining almost all of the nerve responses that were lost. Granted, if I wasn’t so stubborn about continuing to dance this probably wouldn’t have happened. I couldn’t stand being told, “You can’t do it;” because it made me feel less than average, less than human. I would not let myself be defined by my disease.

When the tumor on my left auditory nerve was first discovered, at age 17, the neurosurgeon who removed all of my previous tumors pointed me towards finding someone who specialized in hearing and brain tumors as this was not his field of expertise. I was a bit disappointed because he was such an excellent surgeon: He had the ability to remove the tumors with minimal nerve damage, he had always taken the time to know me as a person and he was extremely supportive through all the procedures from beginning to rehabilitation. However, I appreciated that he didn’t try to be a superhero. I met with four other specialists who gave options of radiation therapy or removal of the tumor, both of which would automatically result in deafness. My mother did extensive research on alternative treatments, and we decided that chemotherapy would be the better choice.
I’m currently on the RAD001 chemotherapy drug trial, run through NYU Langone Medical Center, to treat the tumor on my left auditory nerve. This is the second trial that I’ve participated in. The first one was for Lapatinib, also run by NYU. I was one of four people lucky enough to have had success on Lapatinib but unfortunately, it was only a temporary control of tumor growth.

Tomorrow, I will compete in the Miss Connecticut/USA pageant. My original reason for competing was simple: I felt like it. As time went on, I realized it was for another reason: I wanted to prove myself as a person. To prove that despite having NF2, or any other disease, a person can be more than what society expects of them. I want to show that having NF2 isn’t going to stop me from doing anything I desire. I feel like I showed the doctors when I was told I wouldn’t be able to dance again. And now I want to show the public that having a disease shouldn’t stop a person from achieving goals, like competing in a pageant.

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Regardless of the outcome of the pageant, I look forward to graduating college in the spring. I feel ready to take on the world. And I am not defined by my disease.

Twenty-one-year-old Leanna Scaglione, of Connecticut, is a senior at Endicott College, majoring in creative writing. She is also an intern at the advocacy organization Neurofibromatosis Northeast. Scaglione has continued her various interests in dancing and performing arts with dance solos and the starring role of the “Emcee” in her school’s production of “Cabaret.” She plans on pursuing a career in the theatre arts.
Looking for comfort during a less-than-comfortable diagnosis

Stan Hardin

Society teaches us that men are the “tough” ones. Men don’t want to be considered weak, or unhealthy – which is one reason they don’t see their physicians as often as they should.

Ten years ago this past July, when I was 44, I had to overcome my own inhibitions of visiting the doctor I had seen for regular checkups over the years. Those visits were always standard – that is, except for the dreaded “turn your head and cough” moment, when things became uncomfortable for me. So this appointment, during which I was there for the doctor to examine my penis, was a difficult one.

I wound up being diagnosed with Peyronie’s disease, a condition characterized by the formation of fibrous tissue plaques within the tunica albuginea, usually causing a penile deformity and subsequent erectile dysfunction.

My general physician referred me to an experienced urologist who was trained in treating PD. His expertise went further than just treating me physically. He actually took time to sit and talk with me, and his attention on how PD would affect me psychologically and emotionally made all the difference to my being able to cope. He actually took time to sit and talk with me, and his attention on how PD would affect me psychologically and emotionally made all the difference to my being able to cope.
In 2002, with the Internet still in its infancy, there was nothing available online about PD to help me. So I created my own site and, eventually, a nonprofit advocacy organization. With exposure on the Internet came connections with other men suffering from PD, and through this communication I have made several interesting observations.

What stood out most prominently was the men feeling that male physicians themselves were uncomfortable talking to men with PD. Since this is already an awkward situation, any physician who appears this way will make his patients that much more uncomfortable. I believe that the “turn your head and cough” moment resides within the experience of men with PD much more profoundly.

There is also a general feeling of helplessness about this disorder, as evident by two patient comments on our site:

*I’m 31, married and too young for PD, I’ve had it for 2 ½ years. The urologist told me to take Vitamin E and that there is no treatment; he scheduled me for a follow up appointment. I never went, what’s the point?*

And:

*I have had PD for two years… My doctor sent me to a specialist, who told me that if I had been looking at PD on the internet, that I knew more about the disease than he did… I am 57 years old and very surprised at the dismal options for real help out there!*
The importance of communication cannot be overstated.

It’s clear to me that any physician who examines a man with PD – and with any “below the waist” disorder – needs to be aware of, and sensitive to, the patient’s uneasiness about being examined and being diagnosed with this type of disease. The importance of communication cannot be overstated.

I now know how fortunate I was to have a urologist who understood the complexity that surrounds a diagnosis of PD, and who came to my level and made me feel comfortable with the disease and talking about it. Even after a diagnosis of PD, I can proudly proclaim that I am still a man – and also an active participant in my health care.

*Stan Hardin, of Colorado Springs, CO is founder and president of* Association of Peyronie’s Disease Advocates, *a nonprofit organization dedicated to the education and awareness about PD, The clinical information from the APDA is overseen by some of the most renowned urologists who research Peyronie’s disease and treat men with PD.*
About Inspire

Princeton, NJ-based Inspire builds and manages peer-to-peer online support communities for patients and caregivers, in partnership with national patient advocacy organizations, and helps life science organizations connect with patients.

Inspire builds and manages these communities in partnership with more than 80 national patient advocacy and support organizations. For more information, go to corp.inspire.com, or email team@inspire.com. Follow Inspire on Twitter at www.twitter.com/teaminspire, on Pinterest at pinterest.com/inspiredotcom, and on Facebook at www.facebook.com/Inspiredotcom.

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