

Giving a Voice to Patients and Caregivers

Melissa Thomason, Margaret Toman, Matthew Potter

A key part of patient and family engagement involves listening to patients and keeping their perspective in mind. This article provides a chance for patients and family caregivers to tell their stories.

Dissecting Care: A Patient Advisor's Story

Melissa Thomason

I was 35 weeks pregnant in October of 2008 when my aorta dissected from just above the aortic root down through the entire descending aorta. I can still recall every moment of the dissection. It plays through my mind often, in slow motion, as if it were a dream. I will never forget it; blinding pain stabbed through my teeth and then pulsed through my jaw; my throat tightened, then my chest; finally, aching pressure filled my abdomen. It felt like my insides were spilling open, cracking and crunching like the crystals in an instant heat pack, exploding from top to bottom. Everything went black, and I screamed for my husband. Doctors did an emergency Cesarean section to deliver my healthy baby boy, and then I was airlifted for open heart surgery. I was in the hospital for 38 grueling days. Recovery was slow and painful, and I cried tears of joy when I finally walked through the front door of my home with my newborn son.

I wish I could say that my medical journey ended there, but it did not. Six months after the dissection, I was diagnosed with a rare connective tissue disorder called Loeys-Dietz syndrome, and doctors found a 6.2-centimeter aneurysm near the top of my descending aorta. In June of 2009, my cardiac surgeon delivered the devastating news I dreaded. "We have to do more surgeries," he said. "We need to replace your *entire* aorta."

So they did. In 12 months, I survived 3 open heart surgeries, one of which required an enormous thoracoabdominal incision. The pain was relentless and overwhelming some days. As soon as I recovered from one surgery, I went back into the operating room for another. The toll that kind of trauma takes on one's body—and on one's psyche—is incomprehensible. I began having nightmares. When all of the surgeries were finally over, I desperately needed a way to process the grief, and I found it in my local patient advisory council.

The Power of Patient Stories: Tell Them!

I became a patient and family advisor in the spring of 2011, and I learned very quickly that few things are more powerful than a true patient story. Patient stories add physical essence to intangible concepts like pain, compassion, anguish, or collaboration. Stories put faces on statistics and patient experience scores, and they remind health care workers why they became caretakers in the first place. Strategic storytelling is a valuable tool for engaging patients. It can be so simple to do, and yet it can truly transform a facility's culture. I am so glad that it was one of the first engagement strategies I learned.

Stories are powerful and therapeutic; thus it is no surprise that I began to heal, as I told my story over and over throughout my first year as an advisor. The nightmares faded and, finally, I felt whole again.

The Heart of Engagement

There is so much I could say about patient engagement; I could talk about the value of peer support networks, the power of patient advisory councils, strategies to engage patients by the bedside, cost transparency, or payment reform. We could talk about it all for days and not repeat ourselves. Still, I believe the most important thing I can say to providers is "Thank you."

You see, patient engagement is born out of partnerships, and partnerships are born out of trust. And I have found that the easiest way to build trust is just to be sincere. So, I want to express my sincere thanks to health care workers and providers for choosing occupations in health care. Your sacrifices make all the difference in the world to people like me. NCMJ

Acknowledgments

Potential conflicts of interest. M.T. has no relevant conflicts of interest.

Electronically published July 1, 2015.

Address correspondence to Ms. Melissa Thomason, 2069 Pinetops Crisp Rd, Pinetops, NC 27864 (mthomason@embarqmail.com); Ms. Margaret Toman, 109 Halstead Cir, Garner, NC 27529 (margaret.tmn@gmail.com); or Mr. Matthew Potter, 3460 Dixiana Ln, Pfafftown, NC 27040 (pottmm5@gmail.com).

NC Med J. 2015;76(3):165-167. ©2015 by the North Carolina Institute of Medicine and The Duke Endowment. All rights reserved. 0029-2559/2015/76306

Melody

Margaret Toman

My mother is 101 years old and in the advanced stages of Alzheimer's disease. For 15 years I have accompanied her through every stage of her illness—confusion, forgetfulness, accusations, and wandering. My mother once painted the lampshades with Revlon's Fire and Ice lipstick and stuck wads of Big Red chewing gum on her closet wall, declaring that they would hatch someday. Along the way I have adjusted hope, honed patience, fine-tuned empathy, and stumbled from denial toward acceptance, still elusive. In her heyday, my mother exhibited a visceral joy in living and in love that are the hallmarks of a stellar human being. The fact that 5 million other people in the United States and 50 million people worldwide face the same enemy does not deter me from the notion that this disease is terribly unfair. I advocate for increased funding for research into anything that might solve the mystery of Alzheimer's disease.

Caregivers, many of whom are elderly or have disabilities themselves, walk a high wire buffeted by winds of recession, unemployment, drug shortages, anticipatory grief, unexpected crises, fixed incomes, rising costs, and repeated threats to social programs, the elimination of which would cause many of these caregivers to fall. I advocate for strengthening these social programs.

Monday through Friday I take my mother to adult daycare where she enjoys a lively atmosphere and where the staff medicate, feed, toilet, and celebrate her. I take care of her alone on weeknights and weekends with the support of Frank Sinatra, Lawrence Welk, and our fat cat Velcro, who cares for us both. This arrangement enriches her life and rescues mine, allowing me on weekdays to direct frustration into positive action on aging-related boards and coalitions. There, as a caregiver representative, I share the challenges and the joys of caregiving with good people trying to make a difference, many of whom know only abstractly the reality that my mother and I face every day. I advocate for adult daycare as the most loving, most economical, and most practical option for our rapidly aging populace. There are 106 daycares in 54 counties in North Carolina, which saves the state \$60,000 a year. If we are to keep people out of expensive institutions, funding is needed for many more.

With a sharp eye on how my mother is responding on any given day, I take her to carefully chosen events such as author talks, quiet restaurants, and concerts playing music of her taste. Reactions from people around us vary from friendly and welcoming, to cool and distant, to moving completely away. I protect her fiercely from being minimized, ignored, neglected, dismissed, or discarded by our culture's peculiar attitude toward the very old. I advocate for empathy and age sensitivity training for the very young.

Caregiving and advocacy sometimes merge. When I am impatient with my mother and overcome it, when I grow

bored as she so slowly drinks her Ensure but let her finish anyway, when I want desperately to go to bed but stay up because she is reacting positively to a television program, I am advocating for her right to be as present as she can, protecting her preferences and inclinations, and supporting whatever good moments there are. She deserves no less.

Caregiving at its best is more melody than dirge, the discordances offset by grace notes that sometimes rise to the level of requiem in the most difficult moments. Love is resilient. I have admired my mother's strengths and grieved her losses every day for the past 15 years. There is nothing unusual about this. This is what caregivers, mostly ordinary people with high standards for love, are doing all over this state and country, invisibly, every day, at great cost and for free. They deserve reliable respite, dependable financial and moral support, and unwavering compassion—all of which must sometimes span many months and years.

My mother and I are approaching a time when I must protect her from my own desire to keep her forever. I advocate for love and, when it is time, for letting go. NCMJ

Acknowledgments

Potential conflicts of interest. M.T. has no relevant conflicts of interest.

Patient Engagement: A Matter of People

Matthew Potter

There are many ways in which patients and families can advocate. There are avenues such as patient and family advisory committees. There are countless committees, town hall meetings, listening sessions, and opportunities to share input. The input can range from concerns about client rights, to collaboration with providers, to even the chance to rewrite or shape new service definitions. I have a mixture of many of these experiences in my history; all have been valuable, and all are worth discussing. However, the focus of my article is something entirely different. The fact is that, even with all the formal avenues available to facilitate patient engagement, the most important ways to engage happen on a much more personal, organic level, and I feel that often gets lost in the scope and magnitude of the larger discussion.

I have dealt with many doctors, many hardships, and many procedures. I would be remiss to say I encountered any "bad" doctors; they all did their jobs to the best of their knowledge and abilities, and I am in a much better place because of all of them. However, they have varied in the degree to which they were likely to listen to my input. To use a specific example, there was one instance when I had a dangerous fever, and the traditional course of treatment involved an ice bath. I was concerned and asked if anything else could be tried first. In this case, a nurse offered to attempt a dose of acetaminophen to see if that would break the fever. Mercifully, it did,

and I was able to avoid a needlessly taxing course of treatment, all because I was engaged in care.

Of course, patient engagement does not always mean acceding to the patient's wishes; there are instances when patients need to break their routines or do things they would otherwise refuse to do, for their own health and safety. There are times when health care professionals need to make executive decisions. Some doctors, however, seem to fear letting go of that power. It is entirely understandable why. Patients frequently have their very lives in the care of their doctors, and I cannot begin to fathom that pressure. Nonetheless, allowing patients to be more involved in their

care not only makes the patients feel more respected, it also may improve results.

It is a fine line to walk between responsible engagement and neglect of duty. My point is that engagement can improve medicine just as much as a new pill or procedure, and it will not take an act of Congress or God to begin affecting change. It starts with 3 simple things: dialogue, understanding, and mutual respect between people. NCMJ

Acknowledgments

Potential conflicts of interest. M.P. has no relevant conflicts of interest.