

Finding Your Voice as a Patient Advocate: A Bed's Eye View

Tiffany Christensen

My mother was pressing her back against the wall with such force it looked as though she was attempting to be invisible. Perhaps she was. This was the day I told my doctor that his insensitive comments were so hurtful I no longer wanted him as my physician. I handed him Bill Moyers's book, *Healing and the Mind*,¹ and wished him luck. I was only a teenager when I fired my first doctor, but this was my job; I was training to be my own patient advocate.

As a life-long patient, born with cystic fibrosis and having received two double lung transplants, I know all too well what can happen if I let my guard down in a health care setting. Does the IV bag hanging above my bed have my name on it or is it for Bob down the hall? If I'm being told I need invasive treatment, how can I know that is my best option? When I have three specialists, and they are offering me three different solutions, whose recommendation do I follow? Perhaps the greatest irony of illness is that, in today's complicated health care system, when a patient is at their worst is exactly when they need to be at their best.

Over the years, I have learned that being hospitalized is not a time to relax and heal but rather when I must assume responsibility for steering my own health care ship. If I am too sick to stand at the helm, I must have a friend or family member take over for me. I know now that it is my job to be knowledgeable about my disease process, remain aware of what is being done to and around me, and to find the strength to assert boundaries when my physical or emotional well-being is in jeopardy. In a country where between 44,000 and 98,000 people die each year from medical error,² being an informed and alert advocate is not a choice but a necessity.

Medical Advocacy

In most ways, no one will ever know my body better than me. After all, we have been together from the start. I know how my body reacts to medications, what each pain and wheeze indicates, and what treatments have worked best for me in the past. While this is all true, it does not change the fact that, even after all these years, when the team of doctors walk into my exam room I become a deer in the headlights. I stutter, I stumble, and my mind goes blank.

One important part to being a medical advocate is thinking ahead. For example, bring a list of your medications and your questions to every appointment and admission. During your time with the doctor make notes about any changes, suggestions, or regimens you discuss. You may think you will remember it later, but chances are you will have forgotten by the time you reach your car.

If you find yourself in a situation where you or someone you love feels overwhelmed by medical jargon, rushed into making a health care decision, or is uncomfortable with the decisions being made try the three steps listed below and use them as an anchor.

"Perhaps the greatest irony of illness is that, in today's complicated health care system, when a patient is at their worst is exactly when they need to be at their best."

1. **Slow down the conversation.** Simply saying something like "I'm sorry, I'm feeling overwhelmed. Can I take a moment?" can give you the space you need to absorb the information at hand and help you reestablish control.
2. **State your concerns and ask for clarity.** Some examples of this may be, "I'm sorry, this isn't making sense to me. Can you go back and tell me why you want to do this?" or "This idea makes me uncomfortable. I am concerned

Tiffany Christensen is an author and public speaker. She currently is traveling throughout North Carolina with Project Compassion presenting a grant-funded patient advocacy workshop entitled "Finding Your Voice." Learn more at <http://www.sickgirlspeaks.com> and <http://www.project-compassion.org>.

that this solution will make things worse, not better.” Make sure you voice your opinions, cite relevant past experience and, most importantly, make the professional’s recommendation into a dialogue, not a decree.

3. **Propose your solution.** Sometimes a patient advocate may have a way of approaching a problem that the professional has never considered. You should propose a solution that makes sense to you. For example, you might say, “I am not ready to move forward with this yet. I need to talk to my other specialists before I make any decisions. I will get back to you after I have talked with them.” Another proposed solution may be, “Given what I know about my body, I would like to try the least invasive treatment first. I will give it a month and if that doesn’t work, we can revisit the more invasive procedure.”

You have the right to be a partner in your own health care. That can be difficult when you are overwhelmed, scared, or feeling ill. Using these three steps, you have a basic guide for being an effective medical advocate. As you develop your own model for being a successful advocate, remember to be a partner in your care and remain a humble, polite, and persistent squeaky wheel.

Emotional Advocacy

Being sick feels like being out of control. As patients, we are being pushed in a wheelchair, moving at a speed and on a route not determined by us. We are waiting for people to bring us food, water, medicine, maybe even oxygen. On a good day it is humbling; on a bad day it is humiliating. While we often think of advocacy as keeping someone safe physically, there is also value in keeping someone safe emotionally.

In my years of waking up in the hospital to bright overhead lights and a team of doctors, residents, and interns surrounding my bed, I have been asked more questions than I care to remember. “How’s the pain today?” “Did you go the bathroom?” “Do you still have a fever?” In all of the questions, one aspect remains the same: the inquiries are related to my physical body and never to my emotional health. It is easy to begin to feel like an object, less than human, merely something to be studied. In order to cope with these unpleasant feelings, I have found it is vital to be proactive about my emotional care in the same way I advocate for myself physically.

When I was gravely ill with chronic rejection, I sought out the counsel of a therapist. I have never made a wiser choice in my life. There are so many intense emotions that come with illness: feeling like you have lost your identity, the uncertainty of tomorrow, the deep loss of purpose. I was surprised to find that my family and friends were not the sanctuary for these emotions I once imagined they would be. They love me deeply, but we immediately began to protect each other from our pain; we all worried about burdening the other with heavy emotion. I needed a safe place to go to vent my deepest fears, hurts, and sadness. I believe that without this outlet, I might not be alive today. My emotions were so intense that without

the opportunity to give them voice, it is likely the stress would have caused a faster physical decline.

Being an emotional advocate might mean being the “safe person” for someone experiencing a health crisis. It might be the patient herself setting boundaries with those activities or individuals which cause them undue stress. It could be as simple as creating a visiting schedule to avoid the exhaustion that can come from having too many visitors when you are trying to recover. Emotional advocacy goes hand in hand with medical advocacy; I have found it nearly impossible for one to succeed without the other. Being sick feels like being out of control, but there is always the chance to heal, grow, and become stronger emotionally, regardless of the physical outcome.

Systematic Obstacles to Effective Advocacy

In the 35 years I have been a patient, I have witnessed a shift in our health care culture toward patient advocacy. There was a time when my opinions were considered more “cute” than valuable. Today, in many ways, I am a partner in my health care and my perspective is respected. Individual health care professionals are taking up the cause of patient advocacy. Entire health care systems are investigating ways to provide more patient-centered care, examining pro-active options such as apologizing for mistakes, improving patient/professional communication, and designing a real Patients’ Bill of Rights. All of this is certainly moving us into an age of patient empowerment, where patient advocacy is accepted and part of the norm.

The benefits of this shift can be seen in favor of both the professional and the patient. When patients participate in shared decision-making with their caregivers, they are more likely to comply with recommended treatment.³ Health outcomes improve, costs decrease, and patient satisfaction increases.^{4,5}

For all of the changes, benefits, and positive results that come from allowing patients to be more proactive in their care, I find there are still mixed messages about “who is boss.” For any advocate, there exists an area of the health care system that is largely undefined and worthy of caution. If a patient chooses to advocate for herself and not follow the direction of her physician, she may find herself being written up as going “against medical advice” (AMA). While anyone can understand the need for doctors and health centers to protect themselves against unwise patient choices or poor outcomes, going AMA can carry with it serious ramifications. For example, if I were to go AMA during a time in which I was waiting for a lung transplant, I would risk being taken off the list at my home transplant center. Patients being discharged AMA are also at risk for insurance companies refusing to pay the hospital expenses incurred before going AMA.

Less dramatic than AMA is the ever-threatening “non-compliance” label, which can hold consequences similar to going AMA and can, at the very least, make future health care professionals see you through the lens of “difficult patient.” What makes these labels all the more ominous is the lack of

a clear understanding as to what constitutes compliance; guidelines outlining what qualifies a patient for one of these labels simply do not exist. When a patient is given such a label, it is by the arbitrary hand that happens to be writing in the chart or filling out the paperwork.

We are taught that patients have the “right to refuse.” But is that true? With labels like non-compliant and AMA looming over our heads, how honest is it to say we have that right? Can a patient trust herself to advocate in a system which arbitrarily deems them out of line and unable to make the right decision? Until the terms non-compliant and AMA become clearly defined, patient advocates will continue to walk a dangerous and invisible line. It is essential, as we move into this new health care paradigm, that we find ways to formalize the role and power of patient advocacy for patients, health care students, and professionals.

Opportunities of Illness

Being a patient advocate means something different for everyone. At the heart of advocacy, however, you may find great lessons in trust, compassion, and self-discovery. Through my illness journey I have learned to trust myself as an advocate, worthy of a voice even in a room of medical experts with impressive degrees. As a person who has lived with a debilitating illness, I know what it is to be seen as “less than” because I am not living up to society’s expectations. By emotionally advocating on my own behalf, I have been able to experience the peace and joy that comes when we strip away our identity and discover our true, permanent self. Because I believed in my right to be worthwhile even as a sick person, I have been left with a deep impression of what really matters in life. Today, I am healthy. But I know I am no better today than when I could not get off of my couch. I will carry the lessons of illness with me always and for that I am grateful. **NCMJ**

REFERENCES

- 1 Moyers B, ed. *Healing and the Mind*. New York, NY: Random House; 1993.
- 2 Kohn LT, Corrigan JM, Donaldson MS, eds; Committee on Quality of Health Care in America, Institute of Medicine. *To Err Is Human: Building A Safer Health System*. Washington, DC: National Academy Press; 1999.
- 3 Rider E, Hinrichs M, Lown B. A model for communication skills assessment across the undergraduate curriculum. *Med Teach*. 2006;28(5):e127-134.
- 4 Yedidia M. Transforming doctor-patient relationships to promote patient centered care: lessons from palliative care. *J Pain Symptom Manage*. 2007;33:40-57.
- 5 Neumann M, Wirtz M, Bollschweiler E, et al. Determinants and patient-reported long-term outcomes of physician empathy in oncology: a structural equation modeling approach. *Patient Educ Couns*. 2007;69(1-3):63-75.