

## Connecting the Dots: From Family Advocacy to Patient Safety in the Hospital

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### Voice of the Patient and Family

*In this personal essay, a mother and advocate shares insights she gained after her daughter's tragic death.*

[By Martha Deed, PhD](#) <sup>[1]</sup>

Each time I sign "patient advocate" after my name, I hesitate. Patient advocate on what basis? Who awarded me that title?

I am a psychologist. Retired, but a psychologist nonetheless. Licensed by the state of New York, where I conducted social justice intervention research along with my clinical practice. At the time of the events outlined in this article, I held two state appointments: Psychologist member of the Access to Patient Records Program in the state Education Department and family and professional member of Surrogate Court's Medical Decision-Making Program.

The Surrogate Court's panel assists people who are legally incompetent and who have no family member to authorize treatment or withholding of treatment. When such decisions are needed, a panel is appointed to work on behalf of that person to ensure that humane and medically viable decisions are made. My formal training in patient advocacy comes from the seminars required by the state prior to being seated on a panel. This does not, however, make me a professional patient advocate.

Although patient advocates may be professional staff in a hospital, a patient's family members also become patient advocates when needed. However, the two types of patient advocates – professional or family member – may function from very different knowledge bases.

What patient safety professionals need to understand is that failure to recognize the limited knowledge of even an apparently knowledgeable family advocate can result in confusion and ineffective patient safety interventions. Inaccurate or partial information-sharing with the family advocate may further impair patient safety.



I become a patient advocate when family members need me to be one. That was the case with my 36-year-old daughter, Millie, who was chronically ill with Behcet's disease (an autoimmune disease that causes vasculitis anywhere in the body). Millie designated me her advocate through multiple medical emergencies and hospitalizations. I knew her wishes, and I attempted to follow them in my interactions with hospital staff.

My knowledge of Millie's disease, her response to various medications, and her complicated medical history were superior to her treatment providers' knowledge of Millie. Few of them had ever encountered a person with Behcet's disease. None of the people treating her had ever spoken to her about how she wished her illness to be handled.

But there were sharp boundaries to my knowledge. Basically, I knew only what Millie's previous illnesses had taught me. Each new hospitalization required a steep learning curve.

The last hospital was not treating Millie for Behcet's. They were treating her in the ICU for respiratory failure due to swine flu. Behcet's, to them, was an interesting side issue that they had little time for in an emergency.

I knew very little about lung function, but previous experience had convinced me that Behcet's must be accounted for in every treatment decision. For me, it was not an either/or situation. It was both/and. My

concern, based on years of medical crises, was that if you ignore Behcet's, then Behcet's will defeat your best efforts.

In one example, Millie and I objected to the routine use of blood thinners to prevent clot formation. She was already on high doses of ibuprofen and steroids to control Behcet's. As these medications reduce clot formation, we didn't think any clot could form.

Blood thinners were administered both with and without our knowledge. Within four days, Millie seriously hemorrhaged from an arterial blood draw and required a transfusion.

This incident set a pattern of mounting concern for Millie's safety in the hospital. Her death, in November 2009, left the following lessons to share:

*If you do not have accurate information about your family member's treatment, you cannot advocate effectively.*

Only after Millie's death did I discover that she had received blood thinners most days. Staff would tell us the blood thinners were discontinued after a transfusion, but would not tell us they had been resumed until the need for the next transfusion arose.

*If staff does not accept documented medical facts about the patient, the hospital's patient safety efforts may fail.*

Millie's temperature was rising by the end of the second hospital week at a time when her doctors were discussing discharge. Although swine flu was gone, both Millie and I believed she was getting sicker. No one took notice, because her temperature was not high enough to satisfy the general definition of fever. But Millie's normal temperature was extremely low and was well-documented.

Millie was immuno-suppressed to control the Behcet's. Thus, I was aware she was at increased risk for infection. But the hospital staff did not acknowledge her immuno-suppressed status.

*Patient safety personnel cannot work effectively if there are gaps in handling a patient's concerns.*

On the fifteenth hospital day, I approached the hospital's patient representative (whom I viewed—accurately or not—as proficient in patient safety) with two requests:

1. That the medical director take a good look at my daughter's chart to see if he could assist
2. That the risk management team be activated to consider what was happening—before it became too late.

I asked if I should contact the state Department of Health, because I was perceiving an utter emergency. Amazingly, I was calm and polite as I made these requests.

Fearing that a call to the health department might slow down treatment decisions rather than speed them up, I did not phone the health department. But I felt I was talking to a brick wall.

When I reviewed Millie's medical record months' later, I discovered that the day after my meeting with the hospital's patient representative, the interdisciplinary team recommended that the hospital's social worker should meet with me, not for my benefit or Millie's, but to suggest I make fewer demands on the representative's time.

*If you don't know who is in charge, your concerns may not be addressed.*

I also didn't know that the doctors were arguing about the cause of Millie's deteriorating condition. Some of them suspected a spinal infection. They were right, as it turned out. But there was no traffic cop directing the discussion.

I didn't know that no one was in charge. I didn't know that my concerns were falling into a bureaucratic black hole.

In fact, a survey of the hospital's compliance with Centers for Medicare and Medicaid requirements had found that it lacked a grievance process:

*"Interviews with [hospital system] leaders, including interviews at the system level, provided no evidence of a formal grievance procedure. . . There is no evidence that the patient is provided with information regarding whom to contact if s/he has a complaint. . .*

*"Cause that led to the nonconformity: Lack of knowledge of requirement for a specific grievance process." (DNV Healthcare Inc., 2010)*

My ignorance about hospital hierarchy, hospital culture, and hospital policy negated any possible benefit my knowledge of Millie could have brought to her care.

Several steps might have made my advocacy experience more effective.

Before hospitalization occurs:

1. Family members can make themselves familiar with the hospital they are most likely to use by looking up their local hospitals on their state health department website. States vary regarding information they make public. Helpful information includes the record of citations and corrective actions that have been taken against the hospital by the Department of Health. Even if the entries are not current, the citation record can alert family members to potential hazards in the hospital.
2. Look up results of patient satisfaction surveys for the hospital. Check for infection rates, medical errors, and mortality and failure to rescue rates as reported by such websites as Hospital Compare (<http://www.hospitalcompare.hhs.gov/> <sup>[2]</sup>)
3. Especially if you have a family member with chronic illness, read a good book on patient safety, so that you do not find yourself trying to learn about patient advocacy under fire. *The Empowered Patient* by Dr. Julia Hallisy ([theempoweredpatient.com](http://theempoweredpatient.com) <sup>[3]</sup>) is almost encyclopedic in scope and practical detail. While it may not be feasible to do everything that Dr. Hallisy recommends, it is very helpful to become aware of the pitfalls and steps she suggests.

Often, however, the hospitalization comes as a surprise and a shock. Under those conditions, it is difficult to operate at one's best.

1. Read the hospital's orientation material carefully. Find out who is in charge of your loved one's case. Be present for rounds by that physician.
2. Make sure that others are available to visit and comfort the patient if you are engaged in advocacy.
3. Have someone stay with the patient as close to 24/7 as possible, because problems can occur day or night. Do not attempt to do it all by yourself.
4. Get some rest yourself so that you can remain helpful and clear thinking.
5. Keep a log, so you do not lose track of what is happening with your family member's care. Include notes of any contact with medical staff. Write your notes as soon as feasible after a conversation. This step can go far in preventing misunderstandings as well as mistakes.
6. The hospital will likely wish the patient or family to designate a single contact person. However, the contact person (you, the patient advocate) can benefit if you have someone with whom to discuss patient's treatment. This back-up person ideally should know the patient well and be someone the patient trusts. The back-up can assist the family advocate with keeping focused, identifying communication or treatment gaps. If this person has had previous advocacy experience at that hospital, it can be a bonus. The back-up can be a relative, friend, clergy, or any other person who is informed about the workings of the local medical community.
7. Always, no matter what, remain polite. This is true even though you should not hesitate to go right up the hospital hierarchy if you sense an emergency.

#### References

DNV Healthcare Inc., for the Centers for Medicare and Medicaid. Nonconformity Notes/Corrective Action Plan Submittal, Medicare Recertification, November 29, 2010, p10.

<http://www.furtherfield.org/friendsofspork/> <sup>[4]</sup>. Visit Dr. Deed's website and blog:  
[www.sporkworld.org/Deed](http://www.sporkworld.org/Deed) <sup>[5]</sup> and <http://sporkworld.tumblr.com/> <sup>[6]</sup>.

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[1] By Martha Deed, PhD: [#deed](#)

[2] <http://www.hospitalcompare.hhs.gov/>: <http://www.hospitalcompare.hhs.gov/>

[3] [theempoweredpatient.com](http://theempoweredpatient.com): <http://www.theempoweredpatient.com>

[4] <http://www.furtherfield.org/friendsofspork/>: <http://www.furtherfield.org/friendsofspork/>

[5] [www.sporkworld.org/Deed](http://www.sporkworld.org/Deed):

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[6] <http://sporkworld.tumblr.com/>: <http://sporkworld.tumblr.com/>

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