Soapbox: Insight into the Difficult Patient

By Wendy Lebov, Ed.D., Partner; Language of Caring

With deep sadness, I want you to know that my big sister Linda passed away last week at age 72.

Linda survived Hodgkins, a catastrophic set of health failures in 2006, countless falls, cellulitis, a hip replacement gone awry, neuropathies, dropfoot, vasculitis, pneumonia, and other more minor ailments too numerous to mention. Her determination, plus the wise and constant counsel of her amazing personal physician, Dr. Caroline Ellis, Pat (her daily physical therapist), multiple specialists, and a team of caregivers in her home, helped Linda come back time and time again to hug her grandchildren, watch over our now 96-year-old mother, and retain a high quality of life.

Throughout Linda’s health journey, people found Linda difficult—very difficult—stubborn, resistant, and irritable.

When she moaned and groaned with pain, people tried to get her to take pain meds, but she refused. She said, “I don’t want to be a zombie. And I need to be on guard, aware of what people are doing. If I’m drugged, I’ll be out of it and at their mercy. I have to stay alert so I can be my own advocate.” Intent on retaining as much control as possible, she rejected symptom relief.

Linda also had a terrible time walking. She had dropfoot and extreme neuropathies in one leg after a failed hip replacement, aggravated further by cellulitis and vasculitis. She also had congestive heart failure and no stamina. Still, she refused to give up walking. She endured a painful brace on her dropfoot and daily physical therapy on her red and swollen legs. She revelled in swimming, walking up to 50 lengths of the pool, where she felt free—walking weightless—without a walker or any other support. Taking Linda shopping or out to dinner was harrowing, because at her best, she could only walk (very slowly, painfully and with a scowl on her face) about 10 steps at a time before needing to sit and rest. We all encouraged her to get a scooter and she vehemently refused, saying, “If I get a scooter, I’ll lose my motivation to walk, and I am not going to be an invalid the rest of my life.”
And, while Linda showered her favorite caregivers with compliments, gifts and accolades, she spoke harshly to people who in any way offended her.

- “Stop chewing gum when you’re standing over me. It’s disgusting that I have to look into your open mouth and watch you chew.”
- “STOP! You’re killing me! Pay attention to what you’re doing.”
- “You said you’d be back in a few minutes. Your few minutes was two hours! Did you forget about me--again?”
- To nurse manager: “I hate that night nurse. She treats me like a piece of meat.”
- You’d better bring some supervisors in here. You have no idea what goes on.”
- To the nurse: “STOP! Do NOT draw my blood. My veins are a mess and I need someone who knows what they’re doing.”
- “Get out. I don’t want you to do this now.”
- “You expect me to eat this? I LIVE from meal to meal, and I wouldn’t give this food to an animal.”
- And she used to say things to me that hurt. I tried to empathize: “It must be horrible enduring so much pain.” And she would reply, “You have NO IDEA, not a clue! You just go about your happy life with no cares in the world. You have NO IDEA what I’m going through.”

_Inherently Difficult or Difficult-for-me?_

Was Linda a challenge to her caregivers and her family? Yes. But a difficult patient? No. I would call her a difficult-for-me patient. In her later years, she spent her life’s energy retaining control over her life, facing one struggle after another, and applying her iron will to maintaining as much normalcy as humanly possible. Linda’s behavior and that of other challenging patients is so often driven by very deep, understandable motives – to retain control as they experience losing it, to contend with the fear of a life-limiting disability or death, to endure sheer discomfort and pain.

Linda’s struggles taught me so much. And I hope Linda’s example will spur you on to have ever more patience and empathy for the people who challenge your composure. Please, recognize that they are people who are trying to survive and not having an easy time of it. They rely on their families and care team to demonstrate lovingkindness in everything we do, regardless of their behavior.

_The next time someone is difficult-for-you:_

1. Stop and breathe.
2. Say to yourself: “This is not about me, this person is_________________ (tune in to the true motive behind the behavior).”
3. Respond with HEART, e.g., “I’m so sorry this is so challenging for you. I want to help.”

“They rely on their families and care team to demonstrate lovingkindness in everything we do, regardless of their behavior.”
Rob Gould, CEO shares his perspective on how Language of Caring is transforming patient engagement at Banner Desert Medical Center.

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

Dame Cicely Saunders
Nurse, physician and founder of hospice movement (1918 - 2005)

Scan, Snap, Savor
Try this the next time you feel overwhelmed with the obligations of the day and you need a break to get your head straight.

In her blog, Kathy Cramer, author of the outstanding book Lead Positive shares this great technique.
Read about a huge increase in the percentage of people who are reading on-line reviews to help them make healthcare choices.

**Good News: Payment Reform Supports Improvements in Chronic Care and Prevention**

In their recent article in *New England Journal of Medicine* Medicare’s Chronic Care Management Payment — Payment Reform for Primary Care, Doctors Samuel Edwards and Bruce Landon describe upcoming changes in physician payments for primary care...changes that, in my view, are likely to improve primary care providers partnering with chronic care patients to manage their diseases much more effectively.

**Excerpts from Doctors Edwards and Landon**

“Many efforts to reform U.S. health care delivery focus on creating a high-performing primary care system that improves value through increased emphasis on access, prevention, and care coordination. Reformers recognize that the fee-for-service system, which restricts payments for primary care to office-based visits, is poorly designed to support the core activities of primary care, which involve substantial time outside office visits for tasks such as care coordination, patient communication, medication refills, and care provided electronically or by telephone.

But this system is about to change. In 2015, the Centers for Medicare and Medicaid Services (CMS) will introduce a non–visit-based payment for chronic care management (CCM) — the most important broadly applicable change it has made to primary care payment to date. Practices caring for beneficiaries with two or more chronic conditions that are expected to last at least 12 months and that confer a significant risk of death, decompensation, or functional decline (a category that includes more than two thirds of Medicare beneficiaries) can receive a monthly fee of approximately $40 per beneficiary. A physician caring for 200 qualifying patients could see additional revenue of roughly $100,000 annually.

To bill for this fee, practices are required to use a certified electronic health record (EHR), offer round-the-clock access to staff who have access to the EHR, maintain a designated practitioner for each patient, and coordinate care through transitions to and from the hospital, specialists, or other providers....
The most substantial additional requirement involves collaboration with the patient on creating and maintaining a comprehensive care plan that includes elements such as a list of health issues, medication-management instructions, and a record of involved social and community services.”

This Payment Reform represents a critical step forward in recognizing that the essential features of primary care — continuity, whole-person focus, comprehensiveness, serving as patients’ first contact for new health issues, and coordination — are not optimally supported by the fee-for-service model. There are several kinks in the new payment system which CMS is currently trying to iron out before launching the reform.

Make the point that in healthcare, anxiety reduction is a powerful driver of the great patient experience. Patients and their families appreciate the provider who makes an effort to reduce their anxiety.

Have your team discuss these questions and share the results:

a. Think about those you serve. Choose one point in your services when the people you serve are most likely to feel anxious.

b. What is one thing you can do to prevent anxiety at that point for the people you serve?

c. In situations where prevention isn’t possible, what can you say to the person that might ease their anxiety?
In his book *The Heart Aroused*, David Whyte argued for a workplace where our souls feel at home enough to release the creative energy residing in the dark depths of our beings. People who work with soul apply their life energies to the mission of their job, to their everyday way of doing it, and to the challenge of doing it even better. Hear Wendy describe concrete strategies that help the wonderful people on our teams feel fully alive and fulfilled in their work.

**HIGHLIGHTS:**
- “The Three C’s” key to soulful work: Commitment, Craft and Community
- Practical positive strategies you can use to advance the 3 C’s
Are Language of Caring Programs Right for Your Organization?
REGISTER FOR A FREE WEBINAR OVERVIEW TO FIND OUT.

- Discover how these blended learning programs are helping organizations achieve breakthroughs in the patient experience and patient/family-centered care, as measured by CAHPS improvement
- Learn how these programs work and their specific components
- Preview our awesome new Client Portal for easy access to videos, all materials and sustainability resources
- Get to know our implementation services that help you jumpstart your strategy and accelerate your results
- Ask your questions!

OR

SIGN UP TODAY!
SPACE IS LIMITED

December 10, 2014
12–1 PM (EST)
REGISTER NOW!

December 17, 2014
12–1 PM (EST)
REGISTER NOW!

Language of Caring
FOR PHYSICIANS
COMMUNICATION ESSENTIALS FOR PATIENT-CENTERED CARE

Language of Caring
FOR STAFF
COMMUNICATION ESSENTIALS FOR A CULTURE OF CARING

Achieving an unparalleled patient experience and a culture of caring through exceptional communication.

If you like this HeartBeat, please forward it to others. If someone else sent this to you, please subscribe at www.languageofcaring.com.

Join our LinkedIn Group “Quality Patient Experience and HCAHPS Improvement” and add to the rich discussions about the quality patient experience. AND please send us an INVITE so we can connect. Thank you!