



# HeartBeat

ON THE QUALITY PATIENT EXPERIENCE™

*Insights, tips, tools and resources to help you achieve the unparalleled patient, family and employee experience*



**RESHAPING  
THE CULTURE  
OF CARE**



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## Soapbox: Being the Leader of Your Own Care Team

*Dorothy Sisneros, M.S., M.B.A., Partner, Language of Caring*

Ever since I was a little girl, I watched my mother suffer through many illnesses until her death a few years ago. As a result, I vowed to take care of myself. I have always focused on my health and well-being, physically and emotionally. Then one day in November 2013, I had this itch under my left armpit. When I scratched it, I felt a lump. For the next few days I didn't say anything to anyone. I figured it was nothing. If I raised my arm over my head I didn't feel the lump. When I put my arm down, I would feel it. This went on for a couple of days. I went through many renditions of what could be, what could happen. Finally, I thought I should call my gynecologist. She said, "Dorothy, I don't think it's anything but let's be safe." We scheduled an appointment for an ultrasound and mammogram. The results didn't look good. I went for a biopsy, and found out it was cancer. Shock, shock, shock. I waited all day for the promised call from my gynecologist or the surgeon to schedule an appointment so a plan could be developed for next steps. It never came. The next morning, I called my gynecologist's office and told them I was concerned about the follow-up and next steps, and hadn't received a call-back. The person answering the phone said, "I am sorry but everybody is at lunch so they can't help you."



### *Everybody's at lunch?*

I am in a panic. My anxiety is sky high. My heart rate is going crazy. I can barely function. And all you can tell me is that everybody's at lunch? I asked that they call me when the office reopened. But at that moment, I also decided I was going to become the leader of my own care.

Anybody who knows me knows that I am a take-charge kind of person. I called Banner MD Anderson in Phoenix. When the operator answered I said, "I am newly-diagnosed with breast cancer. I need to schedule an appointment." The response I got was incredible. "Dorothy, my name is Luis and I am just so sorry to hear about your situation. You must be scared about this. I am going to take care of you." My anxiety decreased immediately. He went on, "Dorothy, I am going to schedule you for the earliest appointment with a surgeon that I can get for you."



When I met with the surgeon a few days later, I clearly stated that I wanted to be involved in my care plan. “Please explain what you are going to do and why. Always have conversations *with* me, not *about* me.” I told Dr. B that I would be her best patient as long as we had an agreed-upon plan and I could be part of my own care team. My care team included my family and friends, as well as the physicians, nurses and techs. And I was its leader. That care team took me through a long journey, from the moment Luis the operator scheduled my first appointment through meetings with surgeons and the oncologist until I finished eighteen months and 211 treatments later.

That’s 211 times for people to get things wrong or 211 times for people to get things right. For the most part, they got things right. But not always. And at those times, it was important for me to speak up.

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“Mistakes can be deadly, and that is why it is important to always check and reaffirm what is being done to you and why, and to question anything that seems out of the ordinary.”

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At one chemo session, the nurse was not focused, not on me or any of the other patients. My sister was with me, but I wasn’t feeling well. I was pretty anxious. But the nurse wasn’t present with me. So I said something to the nursing director as she did her rounds the following week and let her know that I was feeling vulnerable if I were to speak up – she encouraged me to engage and share my concerns. Afterwards I had an opportunity to meet with that nurse and the nursing director to talk about what had happened. I explained to the nurse that it was critical that she be present with her patients, otherwise we can’t be sure she is going to give us the best care. She was totally present in that conversation. The next time she was my chemo nurse, she kindly and generously asked if it was okay if she gave me the treatment that day. I said, “Absolutely, you’re part of the team,” and we had a really great infusion (if there is such a thing as a great infusion).

I always insisted that the nurses and physicians explain what was being done and how it would benefit me. Even if it was the 26th infusion I still wanted to know when they were doing it, what medicines were going into me, and what to expect. One time, a week before my surgery, a wonderful nurse was taking care of me— I remember her clearly—Nancy. Nancy told me there was an order for a new chemo. I said, “Nancy, I think you have a mistake. No one’s talked to me about adding a new chemo to my therapy.” She said, “Well, there is a clear order here.” I told her I wasn’t comfortable with that. She said, “Well, together we’ll figure this out because I am not going to give you anything until we’re both comfortable with the situation.” So she shifted into an advocate role. She checked with my physician and nurse practitioner and the decision was made that I wasn’t going to have that chemo so close to my surgery. What if I hadn’t asserted myself? What if I had just gone along with it? What if Nancy hadn’t worked with me? What might the outcome have been? And what happens to patients who let others drive their care?

I learned that our caregivers are right most of the time, but not all the time. Mistakes can be deadly, and that is why it is important to always check and reaffirm what is being done to you and why, and to question anything that seems out of the ordinary. And the staff must be willing to listen.



### Tips for being the leader of your own care team

1. **Focus on wellness.** Take care of yourself physically and emotionally. This includes following up on any signs of illness promptly.
2. **Seek out caring health care.** If you aren't satisfied with the care you are getting, try another physician or another care facility. Don't accept that 'everybody's at lunch'.
3. **Organize your care team—with yourself as the leader.** In addition to the professional health care team, include your family and friends in your 'care team'. Create a smaller 'inner team' and a larger support team. Consider yourself the head of both teams. This means being actively involved in conversations and decisions about your own care.
4. **Call notice to lapses--and to excellent care.** If you are treated in a way you don't like (being ignored, questions not answered, etc.) bring it to the attention of the person or, if necessary, to his or her supervisor. But don't hold grudges--the person may improve if lapses are brought to his/her notice. Similarly, if you receive exceptional care, tell the person (and his/her supervisor) how much you appreciate it.
5. **Insist on explanation.** You deserve to know what is being done to you and why. Politely but firmly insist that you get an explanation of every test, procedure, medicine, changes in care plan, etc. Ask for a truthful explanation of what you can expect (discomfort, pain, nausea, etc.). Don't be embarrassed to continue to ask throughout your treatment.
6. **Be your own advocate, and recruit others to advocate for you.** If you have a question or concern about any part of your care plan, ask the nurses, technicians, physicians, etc. to help you and clarify it. Don't ignore your questions, and don't let others ignore them.

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“Be your own advocate, and recruit others to advocate for you.”

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*In the end, everyone wants a good outcome and this is a great approach to use so that everyone on the team has a great experience.*

“Be kind whenever possible. It is always possible.”

- Dali Lama



- New at CMS: Consumers can choose health plans based on their preferred doctor. Centers for Medicare and Medicaid services recently announced beta testing of a new 'Doctor Lookup' feature which allows consumers to select a health plan that includes their preferred physician and/or hospital. In response to consumer demand, CMS aims to promote transparency and also support consumers as they shop for a health plan.
- Along with leaders from Dell, Adobe, FedEx, Starbucks, Lowes, and the Service Profit Chain Institute, Language of Caring Partner Dorothy Sisneros presented at the 26th Annual *Compete Through Service* Symposium on November 4-6, 2015 in Scottsdale AZ. The annual *Compete Through Service* Symposium brings the most innovative minds in business and academic thought leaders together to advance the science of service. Dorothy's topic: *Empathic Communication Wins Customer Loyalty! Concrete Tools for Engaging Your Team.*

**STRESSBUSTER**

Invite your staff to bring a laugh-provoking YouTube link to a staff meeting. Establish these requirements:

- Less than 2 minutes long
- Inoffensive and in good taste

At the meeting, show a few and relax into laughter. For an example (a silly video of dancing monkeys). [Watch here.](#)

**STAFF MEETING IDEA****How well do you do on the Patients' Wish List?**

Recently, in the [US News HEALTH column](#), Johns Hopkins' Dr. Peter Pronovost presented a 10-point Patient Wish List developed by Hopkins' folks from patient letters and complaints.

Here's the list from patients' perspectives. Use it to spark discussion about YOUR team's everyday practices.

1. Let me sleep. Do not take vitals throughout the night or draw blood between 10 p.m. and 6 a.m. unless it is critical. If it is critical, please make sure I understand. My sleep helps me recover and feel better.
2. Keep the noise levels down at the nurses' station. This is so important – especially at night when my sleep is needed. Turn off the TV, radio, computer screen, etc., at night in my room, so there's not a glare or noise that can disturb my sleep.
3. Don't lose my personal belongings. Take an inventory and label everything with my name and medical record number so my personal belongings do not get misplaced. These belongings are an extension of me and make me feel more at ease. Taking care of my stuff feels like you are taking care of me.
4. Knock on the door before entering. This shows respect for me as an individual and my privacy. Introduce yourself to me, and shake hands or make eye contact when you do this. Call me by my preferred name (formal or first name).
5. Please keep my white board current and up to date. It gives me a quick reference of who is caring for me and my daily plan. Provide a notebook at the bedside so I can keep all my important papers, cards from my health care team and other staff, etc. in one place. Please make sure my name and my location (nursing unit, room number and room phone) are listed on the front.
6. Update me and my family if you notice changes in my condition. Keep communication open. Please keep me informed of delays. It lessens my anxiety during an already stressful time.
7. Keep my room clean. Mop the floors every day, wipe surfaces to prevent the spread of germs, empty my wastebasket and keep my bathroom really clean so it even smells clean. If you are my housekeeper, please introduce yourself to me and say hello. I like to know who is taking care of me.
8. Listen to me and engage me in my care. Use plain language, and make sure I understand my plan of care.
9. Please orient me to my room and the hospital, so I know where important things are located, how to work the television, how to order food and when my linens may be changed. I am a guest here and don't know these things, yet these are important to me.
10. Please maintain professionalism in ALL areas of the hospital. While you may be on your break, you are still a hospital employee and a reflection of the hospital. How I perceive you is often how I perceive the hospital and care that I am receiving.



## LANGUAGE OF CARING WEBINAR SERIES PRESENTS...

WEDNESDAY,  
January 20,  
2016  
1-2 PM  
(EST)

### Caring for Ourselves So We Can Care for Patients and Families

“Some very talented and socially adept physicians learn to balance compassion with emotional detachment,” writes Dr. Sanaz Majd, “...but for the rest, it’s simply about learning to cope, a survival of the fittest.” Healthcare is a vocation founded on providing care to others from our minds and our hearts. As the demands of healthcare become more intense and complex, many of us are finding ourselves at the edge of physical and emotional depletion, leaving us with the sense that we have nothing left to give—to others or to ourselves. In this webinar, first presented through David Couper Consulting, Dr. Carla Rotering helps those working in healthcare deal with stress and feeling overwhelmed.

**SPACE IS LIMITED  
REGISTER NOW!**

**INDIVIDUAL \$49**  
**GROUP (PER CALL-IN LINE) \$199**

If your system wants to purchase several call-in lines, [contact us](#).

#### WHO SHOULD ATTEND?

- *All caregivers. Everyone who provides patient care of any kind (doctors, nurses, etc.).*

#### WEBINAR FACULTY



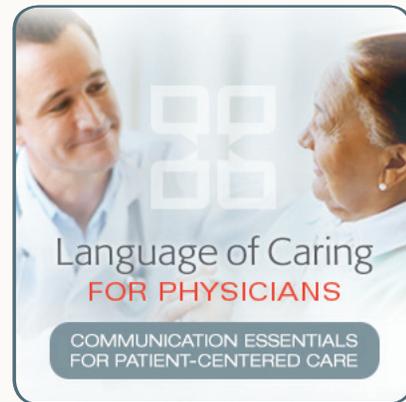
Presented by Carla Rotering, MD, Vice President of Physician Services for Language of Caring and Medical Director of Respiratory and Pulmonary Rehabilitation at two Arizona medical centers. An expert facilitator and exceptional communicator, Dr. Rotering engages her audience with concrete skills they can use to enhance the patient experience as well as their own professional pride and satisfaction. Dr. Rotering is co-developer of the web-based physician engagement program Language of Caring for Physicians and co-author of *The Language of Caring Guide for Physicians: Communication Essentials for Patient-Centered Care*.



## Are Language of Caring Programs Right for Your Organization? REGISTER FOR A FREE WEBINAR OVERVIEW TO FIND OUT.



OR



**Overview of Language of Caring for Staff®**  
December 11, 2015  
12-1 PM (EST)  
**REGISTER NOW!**

**Overview of Language of Caring for Physicians®**  
December 17, 2015  
12-1 PM (EST)  
**REGISTER NOW!**

- 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 Client Portal for easy access to videos, all materials and and sustainability resources
- Get to know our implementation services that help you jumpstart your strategy and accelerate your results
- Ask your questions!

**SIGN UP TODAY!**  
SPACE IS LIMITED

### Contact Us!



314 300 7701



Jill Golde, MS, Dorothy Sisneros, MS, MBA and Wendy Leebov, EdD—partners at Language of Caring.

### Spread the Resources

- Forward this month’s Heartbeat email to others.
- Share and tweet the following link: <http://languageofcaring.com/wp-content/uploads/2015/12/being-leader-of-your-own-care-team.pdf>

Join our LinkedIn Group “Quality Patient Experience and HCAHPS Improvement” and add to the rich discussions.

**PLEASE FOLLOW US!**    