

# In Other Words ... Communicating When Naked--My Perspective as a Patient

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Talking about health and other medical matters had always been easy for me. As an occupational therapist and health-literacy consultant, I felt confident and in charge of conversations no matter which professional hat I was wearing. But after a routine mammogram turned out not to be so routine, I felt more than hatless. I felt naked. Now I had to communicate not as a provider or consultant, but as a patient.

The diagnosis was DCIS (ductal carcinoma in situ, a very early-stage of breast cancer). Ironically, this was a condition I knew a good deal about. The year before, I'd written the National Cancer Institute booklet "[Surgery Options for Women with Early Stage Breast Cancer](#)". But as a patient, I became easily overwhelmed talking with doctors about my diagnosis and treatment options. Since the conversations concerned me directly, I was often so flooded with emotion that I had trouble thinking and remembering.

Conversations eventually got easier, and over time I learned what I needed to learn. I also learned, through no choice of my own, about being a patient. Here are some of the lessons I came away with after communicating "naked." Understanding them, whether you're a patient or a provider, can make a difference in how each of you works with the other.

## **What Patients Need to Do**

**Show up.** This sounds so simple yet can be so hard to do. As a patient, it takes courage to show up for medical appointments when fearing news you don't want to hear or dreading procedures you don't want to have. I'd muster courage by asking my husband or friend to go with me, or having a private "pity party" before appointments and then rewarding myself later for showing up.

Some of the most courageous women I've ever met sat beside me in the waiting room when I went for radiation treatments. We chatted, but usually not about our diagnoses or prognoses. Instead, we talked about the ordinary parts of our lives, such as our commute that morning or what we did over the weekend. We supported each other yet didn't need words to share our experiences as patients.

**Create your own medical record.** As a health-literacy consultant, I sometimes speak to consumers about health communication. One recommendation I make is that people create their own notebooks with important medical information. But did I take my own advice? No, at least not until it felt like medical matters were

way out of control. Creating my own medical record turned out to be one of the most important things I did. My medical record is in a three-ring binder that includes:

>*Medical reports.* I included copies of pathology reports and discharge instructions. Having these so available not only helped me but, at times, also my providers. I remember an early-morning procedure that was almost delayed because the specialist didn't have (or couldn't find) a copy of my surgeon's referral. But thanks to my notebook, I had a copy of the report she needed.

>*Doctors.* I had so many appointments at different facilities that sometimes I felt like a "secret shopper" of medical matters. To keep track of all these providers, I had a section in my notebook for information about each doctor, including a photo (if available), contact information, and directions to his or her office.

>*Questions.* At home, I could think of lots (and lots) of questions I wanted to ask my doctors. But when wearing just a hospital johnny, I struggled to remember any of them. To help, I would make a list of all my questions beforehand so that later all I needed to do was write down the answers.

>*Notes to me.* I found it comforting to write occasional notes and stories about how I felt and what I observed. Not only did they defuse my emotions at the time, but now these notes serve as powerful reminders of my patient experience. I didn't know then what I would do with them, but now they're the core of what I'm writing to you.

>*Important papers.* Many providers asked me similar questions about medications and allergies. I got tired of repeating myself, and so I made a master medication list which each office could copy. I also kept my signed healthcare proxy in the notebook for any health provider who requested it.

>*Kind words.* People were amazingly wonderful. I treasure their support and caring, though honestly couldn't always remember who did what. To help, I made a list of their gifts and other niceties with space to note when I thanked them.

>*Zippered pouch.* I found that a three-hole-punch zippered pouch was a most handy addition to my notebook. I used it as a catch-all for my patient identification cards and doctors' business cards. And when I got tired of fumbling around for a pen to take notes during appointments, I added one to my trusty zippered pouch.

**Learn only as much as you want to know.** What probably surprised me most during this time was that, as a patient, I did not want a lot of "outside" information from the Internet or books. I trusted my doctors to tell me what I needed to know. I also found outside information somewhat scary, as I tended to focus on the worst-case scenarios. I checked with other patients and learned that many of us set limits on how much information we want to have.

**Be in charge of communication.** Life changes forever when you are diagnosed with a serious illness. But I knew from the start that I did not want this diagnosis to be my sole identity. Being in charge of communication was an important way for me to preserve my sense of self. One way I did so was with something I called "breast-free zones." These were times (often at meals) I opted to discuss topics other than my anatomy. Setting limits on the conversation not only helped me but also others who worried about what to say.

Another way I was in charge of communication was by sending out periodic group emails to family and friends with updates about my medical matters. For the sake

of everyone's privacy, I entered their addresses as "bcc" (or blind carbon copy) so others could not see who I was writing to.

**Be nice to yourself.** Similar to the story of Hansel and Gretel, who marked their path with breadcrumbs, I placed treats along my treatment path. Some were small, such as buying my favorite coffee on the way to radiation treatments. Other treats were bigger, including a celebratory party to toast good friends and good health.

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