

Coming to Terms With Language

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Over the years, I have been moved by many wonderful Flaherty lectures, and I am grateful to the Oncology Nursing Society for maintaining the tradition of this lecture as a time for us to remember the heartfelt issues that are the touchstone of oncology nursing. Twenty-two years ago, I was in the audience as Judi Johnson, PhD, RN, FAAN, gave the first “Mara lecture” (Johnson, 1982). She shared with us the vision she and Mara had of living a healthy life in spite of having cancer. I was touched and inspired by Judi’s words and her memories of Mara as a vibrant, active human being who lived life to the fullest. My message is dedicated to Mara and to all those who have shown us what it means to try to maintain balance, dignity, humor, health, and sense of self when confronted with cancer. My message is about language and how we use it.

I have had a lifelong love affair with words, yet the broader concept of language—how it evolved and what it means—did not hold much intellectual or emotional weight for me until the heartrending day when I learned with certainty that my beautiful 18-month-old baby boy was deaf. I had never felt such personal pain. I grieved. I mourned. When I would finally drop off to sleep, it was only to awaken with waves of the awful truth washing over me all over again. Even the simple act of listening to music was intensely painful because I thought the joy it gave me would be unattainable for my son. I also imagined that among the many things that would be lost was any future ease of communication between us. It struck me as particularly cruel that we would not be able to share a love of words—words that are the very essence of all incidental and formal learning, words that form the bonds of relationship, and words that uniquely express personality and humor.

There were few guideposts for the journey we were about to embark on, and every twist and turn in the road brought me back to the question of language. Emily Perl Kingsley (2003) described this awakening better than I can in an essay she called, “Welcome to Holland.” She said,

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared the unique experience to understand it, to imagine how it would feel. It’s like this: When you’re going to have a baby, it’s like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. Michelangelo’s “David.” The gondolas in Venice. You may learn some handy phrases in Italian. It’s all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, “Welcome to Holland.”

“Holland?!?” you say. “What do you mean Holland?? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.” But there’s been a change in the flight plans. They’ve landed in Holland and there you must stay. The important thing is that they haven’t taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It’s just a different place. So you must go out and buy new guidebooks. You must learn a whole new language. And you will meet a whole new group of people you would never have met. It’s just a different place. It’s slower-paced than Italy, less flashy than Italy. But after you’ve been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts. But everyone you know is busy coming and going from Italy . . . and they’re all bragging about what a wonderful time they had there. And for the rest of your life, you will say, “Yes, that’s where I was supposed to go. That’s what I had planned.” And the pain of that will never, ever, ever, go away, because the loss of that dream is a very, very significant loss. But if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

By coincidence, she was writing this at precisely the same time that I was groping my way through my own “Holland.” I was coming to understand that the world of deafness was peopled with opposing factions and there was precious little consensus to help parents. This is a real obstacle because most



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