

Do you understand your diagnosis?

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In the upcoming Winter issue of *CURE* we have a story on health literacy. As most of you who have been there know, this phrase does not relate to how many people who are diagnosed with cancer can read and write. The day I was diagnosed it didn't matter that I had a master's in communication because I heard very little after the words *you have cancer*. For the piece we interviewed Helen Osborne, M.Ed.OTR/L (which means she is also licensed in occupational therapy). Osborne, the founder and president of Health Literacy Consulting, became interested in health literacy in the mid-'90s and has received awards for her "plain English" writing.

She is also the one who determined that health literacy should have its own month and decided it should be October. Osborne consults with lots of folks about how to educate people on health issues, including cancer. In addition to promoting the use of plain language, Osborne speaks on the barriers to understanding health care information. These barriers include the obvious things, such as the inability to read or write or a disability such as dementia. But she also addresses another barrier that we don't consider that often – the emotional impact of information. This points to one of the most ignored aspects of health literacy--emotions and how we often cannot hear when we are trying to figure out the issues of life and death--no matter how much education we have.

Over the years she has written a number of cancer education items for the National Cancer Institute, among them *Surgical Options for Early Stage Breast Cancer*. She laughs about how, a year later, when she was diagnosed with early-stage breast cancer, she had no clue what to do. "I literally wrote the book but it made no difference," Osborne says.

That was how I felt the day I heard I had breast cancer. I could paint you a picture of what the room looked like, but I don't remember any of the words. At one point a few years ago, my oncologist and I were asked to do a skit for a meeting of oncology fellows where he read my actual pathology report into a microphone while I listened. When he said something that set off an emotional or mental reaction in me, I would start saying out loud what I was thinking. Of course, he is still telling me important information, but I'm not hearing it because my own internal dialogue is going. The oncology fellows got it in a way that no amount of classroom instruction could – and I have heard from more than one of them that they now know their patients need information repeated before they actually hear it.

This brings up another issue about literacy. Osborne says the only way to guarantee that cancer patients get the information they need is to get to know them and how they communicate. She gave as an example a time when her own oncologist was discussing with her the use of hormonal agents. Osborne concedes that she does not "do" numbers despite being surrounded by a husband and children who are all numbers driven, so when her oncologist started giving

statistics on relative risk and absolute risk, Osborne zoned out. "Then she did something so simple. She took her right arm and held it really high and said, 'I see this as your benefit,' "Osborne says. "Then she took her other hand and held it low and said, 'this is possibility of side effects.'" She made it clear and simple to Osborne, who decided to do the drug that she had had misgivings about.

Osborne recalls the reaction of her hospital co-workers when she began talking about health literacy in the mid-'90s, asking if she meant the ability to read. Today, it's an issue on the national agenda. To read and hear stories about the importance of health literacy, go to Osborne's [website](#)