

IN EVERY ISSUE

# The More You Know

BY HELEN OSBORNE

*How much is enough when it comes to cancer information?*

I'm a health care provider and health literacy consultant. I often help organizations communicate medical information in a way that is understandable for patients and their families. Obviously, I'm a believer in the power of information.

But I started to question this belief when I was the patient, not provider. Four years ago, I was diagnosed with early-stage breast cancer. This diagnosis not only changed me physically but also made a profound difference in the way I think about health communication.

Before my diagnosis, I assumed that more health information was always better than less. When writing patient education materials, I liked to include a statement like this: "Learn as much as you can about your illness and its treatment."

Now it was me reading such directives. In truth, I didn't always want to learn more. Admittedly, I was fairly knowledgeable about breast cancer as, ironically, not too long before my diagnosis I helped write and edit the National Cancer Institute's booklet "Surgery Choices for Women with Early-Stage Breast Cancer" ([www.cancer.gov/cancertopics/breast-cancer-surgery-choices](http://www.cancer.gov/cancertopics/breast-cancer-surgery-choices)).

Now diagnosed, I spoke at length with my doctors about treatment options and outcomes. I also talked with a few women in situations like my own. Most of the time, that was sufficient information for me. I found that I would get more confused and overwhelmed when I read a lot of articles about research or looked at many websites for patients. I also found that new information often raised my level of anxiety as I would zero in on the worst possible outcome and be certain that it would happen to me.

So what's the right amount of cancer information? The lesson I've learned from being on both sides of the health care conversation is that there is no right amount. Just as our physiology differs, so too does our need and desire for health information.

For instance, Joan was my dear friend and neighbor when diagnosed with colon cancer in her mid-40s. She and her husband, Eric, were always active information-seekers and this proved true for her diagnosis, too. Alone and together, they spent many hours researching her treatment options. They both said that this extensive research process helped them cope with what turned out to be a dire prognosis.

Another friend, Paula, was the director of our town's public library. She was diagnosed with an aggressive form of lung cancer around the same time I received my diagnosis. We met for breakfast to compare notes about our cancer journeys. I shared that one of my most surprising discoveries was that I didn't always want to learn more—and that this was OK. I still remember Paula touching my arm with tears streaming down her face. "You mean, I don't have to keep learning more?" She added, "Until now, I had this niggling feeling that I was not doing enough for my health if I didn't go to the Internet at least twice a week."

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'You mean, I don't have to keep learning more?' ☒

So what is the right amount of cancer information *for you*? Perhaps if you are like Joan and Eric, you will want to find out everything you can. Or if you are more like Paula, then a limited amount of online research may be sufficient. Or maybe you are like me and have an adequate baseline of understanding and look primarily to your treatment team to teach you more.

You are the only one who knows how much information is enough. Best wishes doing your research—or not, if you prefer.

—Helen Osborne, MEd, OTR/L, is the founder and president of Health Literacy Consulting ([www.healthliteracy.com](http://www.healthliteracy.com)) and the founding director of Health Literacy Month ([www.healthliteracymonth.org](http://www.healthliteracymonth.org)).