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How Much Do You Want -- or Need -- to Know?

By Jessie Gruman
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Four times, I have been diagnosed with life-threatening diseases. Each time, the news stopped me cold; it landed me in a hospital; it forced me to rearrange my life and rethink my responsibilities while my body was battered by drugs and surgery.

And it immersed me in a cold, uncomfortable reality that is familiar to anyone who has received a sudden diagnosis of serious illness. Our connections, our skills in finding information and acting on it, our abilities to cope -- all of which are necessary for making the right decisions and getting the right care -- feel suddenly inadequate.

But through my own experience -- as well as the experience of talking to more than 200 others who have faced a devastating diagnosis -- I've discovered that people are remarkably resilient once they gather the information they need to reconstitute their immediate futures.

There is no time in one's life when it is more important to make judicious use of the scientific information now abundantly available to us -- and there is no time when you feel less able to do so.

What's more, people have very different ideas about how much they *want* to know about their disease or the disease of someone they love. Suzanne Miller, a psychologist at the Fox Chase Cancer Center in Philadelphia, found that people tend toward being either what she calls "blunters" (those who have little interest in seeking out information or learning about risks) or "monitors" (who track down the details, for example, of the molecular structure of their pancreas -- online, at the library and in conversation).

Regardless of whether you are a blunter or a monitor, there are four main reasons you need a basic understanding of your disease and its treatment.

Collecting information is the first crucial step that allows you to make decisions that are right for you. You can say yes or no to a doctor's recommendations, but you need some basic knowledge to be able to serve your own best interests.

Second, you need a mental model of what is happening to you. Until you have one, it is difficult to make sense of the actions you must take to participate in your treatment. If you understand basically what the pills do to keep your condition in check, you will be more likely to take them as directed. If you know

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what a certain test will tell the doctor, you'll be more likely to show up for it.

Third, you need to realize that what doctors consider state-of-the-art treatment in Connecticut may be very different from what doctors recommend in the Washington area. This means you may have more choices than you realize. It does not mean, however, that you need to cram a complete medical education into the days following a diagnosis. You simply need to know enough to ask informed questions.

The fourth reason you need to know about your condition and its treatment is that you -- and probably your partner or family member -- will need to keep a vigilant eye on your care. Most patients do not have access to an electronic record that includes their entire health history, test results and treatment plan. Each new doctor and institution you visit may have to piece together the information that is relevant to your care. It is common knowledge that such decentralization can lead to mistakes.

Educating yourself about your disease can be difficult when what you really want to do is delegate the responsibility for making decisions to your doctor. Further, the diagnostic process sometimes moves too quickly for deliberative information-gathering. "If you are going to the emergency room and then straight into surgery, there is not a lot of time to learn what this means and to discuss it," noted Janet Baradell, a psychiatric clinical nurse specialist in private practice in North Carolina.

But as Ellen Stovall, president of the National Coalition of Cancer Survivorship and twice the recipient of a cancer diagnosis, puts it: "It is a rare exception that any condition must be responded to within 48 hours. Taking an extra week to see another doctor, get another opinion and do a little more research can make all the difference between getting the wrong treatment or less-good treatment, rather than the right treatment for you."

Even in the midst of an acute medical crisis, most people are able to acquire a workable understanding about their condition and its treatment. Alternatively, a family member or friend can pull together information for you to look over. Shelley McKaye, a nurse leader in pediatrics at Memorial Sloan-Kettering Cancer Center in New York, said: "I always marvel at the ability of families, regardless of their educational level or medical sophistication, to learn this new language of medicine that they don't want to know. They learn it because they have no control, and this is one way to regain a little control."

Miller has found that, although blunters and monitors respond very differently to the glut of information that's available, both represent fairly stable styles of coping. "It is as though blunters are wearing dark glasses while monitors are using a magnifying glass as they selectively attend to the world around them," she said.

Blunters attempt to keep anxiety at bay by avoiding details that might be frightening and by relying on experts. One 47-year-old professor, a classic blunter who had received a diagnosis of prostate cancer, told me: "I would be insulted if some guy read 15 papers on theoretical physics, my own field, and then came in and asked me to help him design an experiment. And I expect the same of my doctor. I pay her. Let her sit down and tell me exactly what I need to know -- what are my choices and what do they mean? That's her job. I have other things to do."

Monitors, on the other hand, are uncomfortable with the unknown. They tend to gain confidence as they gain understanding, even though the monitoring style can rouse anxiety. People who want a lot of information sometimes have trouble figuring out when they have enough of it.

A 38-year-old nonprofit executive with breast cancer recalled, "My doctor went through all the options. I had been completely absorbed in my office since getting my diagnosis on the phone -- on the Web researching things. There were literally millions of Web sites to go through! I had so many questions! I was definitely over-informed. My doctor's first advice was, 'Get off the Internet! You know plenty now.' It was comforting to learn that there was a fine line between information that was helpful and stuff that was just scaring me."

Under stress, people report becoming more extreme and more set in their preference for how much to learn about their condition. A blunter may actively resist learning more. A monitor may spin out on the glut of information available, desperate not to miss that single last fact that will make the difference between their life and their death.

I've heard many stories in which the members of a couple or a family have different information preferences and worked out a method that suited them all: A cousin who's a nurse checking out doctors' credentials; teenagers performing Internet searches for their grandparents, for example.

But I've also heard heartbreaking stories in which the difference in style was the straw that broke the camel's back: the young woman dying of liver cancer who was estranged from her husband because he wanted to examine and expound on every journal article, every blood count, while she wanted to spend her energy enjoying the limited life she had left.

One young lawyer with ovarian cancer told me, "I didn't want to understand about my own cancer; it was too distressing and scary. I didn't want to know the survival statistics or how fast the tumors grow. I had broken up with a boyfriend just before my diagnosis. In trying to be helpful, he came over with a book that was full of this kind of information. I told him, 'No, I don't want to read this.' He told me he thought it was something I needed to do. And I felt like I wasn't being a good patient."

I have reacted differently with each of my four diagnoses. Most recently, when I learned I had colon cancer, I delegated the information-gathering to my husband. He was antsy to do something, and I had no patience for wading through frightening information to find something relevant to my situation. I should also admit that I wasn't that interested in hearing what he found out. The thing that was most helpful was that I finally convinced myself that I should say the things that I was most scared about out loud to him. Most of the time, he responded in a way that calmed me down: "Well, from what I read, I don't think that's what is going to happen." Or "I don't think we know enough about how bad this is to draw any conclusions like that. You need more tests before we'll know."

In the end, whether you prefer to learn a lot about your disease or only the bare minimum, you need to know enough to make choices that are consistent with your preferences, that honor your values and that allow you to move forward, confident that you have made the right decision for you. ·

Jessie Gruman is president of the Washington-based Center for the Advancement of Health. This article

is adapted from her new book, "Aftershock: What to Do When the Doctor Gives You -- or Someone You Love -- a Devastating Diagnosis" (Walker). Comments: health@washpost.com.

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