In today’s fast-shifting patient-centric world, do we know what patients with serious diseases really want when it comes to information about their health? And are pharmaceutical companies listening?

by Carol Weeg

W hen Wendy S. was diagnosed with metastatic breast cancer two years ago, she listened carefully to what her doctor told her about her condition and treatment options, then turned to the Internet for more information. What she found was mostly for people she calls “survivors” – women with earlier-stage breast cancer, who may experience long remissions or even cures. “That’s not going to happen to me,” she says frankly, “but I am surviving, one day at a time. Where’s the information for people like me?”

Good question, and one that led me to others: What kinds of information do people with serious diseases want? How do they want to get it? And are pharmaceutical companies responding?

To try to find the answers, I read several studies about how consumers look for and use pharmaceutical information. Then I interviewed six people with cancer, ranging in age from 38 to 65. In addition to talking to Wendy (who has metastatic breast cancer), I interviewed other people with various types of cancer, including early-stage breast cancer, non-Hodgkin lymphoma, multiple myeloma and prostate cancer. The person who had lived with his cancer longest was diagnosed six years ago; the most recently diagnosed learned he had cancer only a few months ago.

Here’s what I found:

**Tailoring is key**

Patients want only information that applies to their situation, as Wendy’s statement shows. Every patient I talked to mentioned Web sites and brochures for their type of cancer that were not helpful because they were too general or had little information about their particular form of the disease.

Pharmaceutical companies often don’t do a good job of tailoring the message, even with their unbranded disease education Web sites. A study by market research company Mintel found that patients are increasingly looking for information on their own to choose health care treatment. If what they find is information that doesn’t apply to them, they’re going to click away from or discard it. While it may not be practical to provide detailed information about every form and stage of a disease, an overview of a condition should at a minimum contain links to advocacy groups for more information.

**Make information bite-sized**

Getting diagnosed with cancer makes nearly everyone feel anxious, which makes it difficult for patients to understand and remember everything they’re told. In fact, a recent study published in the *Journal of Clinical Oncology* found that most patients who had just been told they had cancer remembered less than half of what their doctors had said.

“Too much information at one time is overwhelming,” said one person I interviewed. “It’s easier to get it in installments.” And having already received bad news, patients are afraid of finding more in what they read. Then there are the side effects of treatment: four of the six patients I talked to referred to their “chemo brain,” claiming that their treatment affected their memory. That’s why the interviewees preferred two forms of communication: brochures or booklets, which

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they could re-read as needed, and Web sites that keep track of content they had read, videos they had watched, and symptom assessors they had used.

Pharmaceutical companies should provide disease and treatment information in multiple formats, from a one-page sheet that doctors can give to the newly diagnosed, to more detailed brochures and Web sites. That way when patients are ready to learn more, they can.

Beware of unintended finger-pointing

Patients may interpret lifestyle advice as implying that they caused their own cancer by making unhealthy choices. This may be surprising, but it probably shouldn’t be: Studies abound that link lifestyle and cancer, including the influence of diet, exercise, weight and stress on developing the disease or having it recur. “I used to live on fast food, and I already feel guilty about that,” said one interviewee. “When I read about how I should watch my diet and get exercise, it just makes me feel worse.”

When pharmaceutical companies’ unbranded Web sites include lifestyle advice, the sites should be careful to position it simply as steps that can help people feel better moving forward.

Create message boards

Patients want to hear from people who have “been there, done that,” as one interviewee put it. All six patients I spoke to participate actively in message boards. What are they looking for? One woman wants a recommendation to an oncologist closer to her home. Another wants to hear from anyone with her form of cancer that’s in remission, and how long they’ve been there. A man wants to hear about the experiences of people who have had a stem cell transplant.

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Pharmaceutical companies typically don’t offer patient message boards, fearing negative posts about their products or side effects. But moderated message boards, where questions and comments need to be approved to be posted, should be considered. This could give patients a sense of community that would include the companies that make the medication they take.

Don’t forget family members

The people I spoke with all have children, ranging from grade school-age to old enough to have families of their own, and they all want information for their loved ones. A woman with an 8- and a 10-year-old would like a book that explains her cancer in language her children can understand. A man with kids in college wants to know how to talk to them about his prognosis. A woman whose adult daughter is helping with her care worries that she’s going to burn out and wants information about support groups for caregivers.

Disease information from pharmaceutical companies for family members is often lacking, and content for caregivers may simply repeat patient information, replacing the word “you” with “your loved one.” Pharmaceutical companies should gear more information specifically to family members and other caregivers.

Provide help with organization

Dealing with a serious illness takes a huge amount of time and organizational skills on the part of patients. A patient may see several doctors, visit an infusion center for his or her treatment, consult a nutritionist and get help from a therapist. This can generate a mountain of paperwork, not to mention insurance forms, all of which the patient should retain.

The people I spoke to want help getting and keeping medical paperwork organized. This includes trackers for treatment and diagnostic scans, appointment reminders, and pages for recording their medical team’s contact information. Some pharmaceutical companies already provide this, and others should consider adding it to what they offer patients.

Keep the message hopeful

Above all, the patients I spoke to want to approach their future with hope. Even when they can’t realistically hope for cure or a long remission of their disease, like Wendy with her metastatic breast cancer, they hope to extend their lives for as long as they have a good quality of life.

The information that pharmaceutical companies creates for patients is often very clinical in nature, sometimes adapted only slightly from what they provide to healthcare providers. Patients are individuals, with jobs, families, hobbies and unique likes and dislikes. In other words, they’re just like you and me, but they’re also living with the physical and emotional consequences of a serious illness. We should keep that in mind.

In the end, the most important thing for a pharmaceutical company is to give patients what they want.

From the patient point of view, having pharmaceutical companies pay attention to the kinds of information they want can make them feel like they’re being heard. And for pharmaceutical companies, it’s just plain good business.