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Layman's Terms

BY CHARLOTTE HUFF

How to translate the language of cancer.

Prognosis. Metastasis. Adjuvant chemotherapy. PET scans. Neutropenia. The world of cancer treatment is strewn with multi-syllabic words, advanced mathematics, and statistics; sometimes it may appear that an advanced degree is needed to understand the basics. That is, if the patient can absorb much beyond that first word: diagnosis.

“They are shooting all of these big words at you—things they will be doing to you,” says Willie Stewart of Shreveport, Louisiana. Stewart, now age 61, was diagnosed in January 2006 with a golf ball-sized lung tumor that was wrapped around a crucial blood vessel, making surgery infeasible. “You are asking questions, and they are trying to answer them the best they can,” he says. “But you still aren’t comprehending.”

Only a small fraction of adults, 12 percent, is considered to be proficient at understanding complex health information, according to the 2003 National Assessment of Adult Literacy. The survey was the federal government’s first effort to quantify levels of health literacy, the ability of individuals to obtain, process, and understand the concepts and terms crucial to making informed medical decisions. Even people with high levels of education and strong literacy skills can face health literacy challenges, the survey found.

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Physicians and other clinicians can further aggravate comprehension problems by relying too much on medical jargon, says Terri Ades, DNP, director of cancer information at the American Cancer Society. “We get so caught up with our medical terminology,” she says. “And we can’t do that when communicating with patients.”

Grasping some of the decisions involved with cancer treatment can be

particularly difficult, given the field's hefty reliance on numbers and technology, Ades says. "When we talk about risks and probabilities, we are really talking above most individuals in terms of their level of understanding."

Gaps in health literacy can also jeopardize medical care. A 2004 review of health literacy research, published in the *Journal of General Internal Medicine*, identified several studies that linked lower literacy levels with a lack of health screenings, such as getting a Pap smear or a mammogram. Another research review, focused on cancer-related studies, found that health literacy was associated with delayed diagnosis, as well as a lower likelihood of patients complying with treatment. The U.S. Department of Health and Human Services made health literacy one of the goals of Healthy People 2010, a blueprint of health objectives for the nation, and has issued a number of booklets designed to promote clearer education, including suggestions to use more pictures and limit the number of health messages.

To boost patient comprehension, some clinicians are asking patients more questions to probe their knowledge or taking a few moments to sketch a drawing or flip through an anatomy book, says Ades and others interviewed. At the American Cancer Society, officials have added more video clips to the website and are developing interactive videos, which incorporate questions to gauge a viewer's understanding. Other groups, such as the Boston-based Foundation for Informed Medical Decision Making (www.informedmedicaldecisions.org; 617-367-2000), are running several research projects to assess videos and other decision-making aids in assisting cancer treatment decisions.

View Survey Results: How Much Do Patient's Understand?

[View Survey Results: How Much Do Patient's Understand?](#)

Beyond Brochures

Too often, though, clinicians may rely on brochures and other densely worded materials to educate patients, says Terry Davis, PhD, a professor of medicine and pediatrics, and director of behavioral science at Feist-Weiller Cancer Center, located at Louisiana State University Health Sciences Center in Shreveport. The clinicians themselves may not know exactly what's in those brochures, she says. Instead, the patient would benefit more if the clinician reviewed the material with the patient, underlining key points, says Davis, a long-time health literacy researcher.

Keep in mind, says Davis, that confused patients don't necessarily ask questions. A certain level of vocabulary and confidence is necessary to cross-examine the doctor, she says, because "nobody wants to look stupid."

A better and more interactive approach is what's sometimes dubbed the teach-back method, Davis says. Doctors ask patients to briefly summarize what they have discussed. As patients relay their version, the oncologist has the opportunity to further clarify or elaborate.

When flummoxed, patients can adopt their own teach-back method, says Helen

Osborne, MEd, OTR/L, author of *Health Literacy from A to Z: Practical Ways to Communicate Your Health Message*. “They can say, ‘I want to make sure I really understand what you are talking about.’ ”

Still, some patients may discover that fear about cancer short-circuits comprehension, says Osborne, who can attest to that personally. She was already specializing in health literacy, including writing consumer booklets for the National Cancer Institute, when she was diagnosed in 2005 with ductal carcinoma in situ, a very early stage of breast cancer.

“To me, the first time I heard the word ‘cancer’ associated with myself, I tuned out everything else,” she says. “I think the role of emotion is incredibly powerful.” (Hear more from Osborne in [Speaking Out](#).)

Stewart describes how he, too, was initially overwhelmed by information and “all those white coats” when he was diagnosed at LSU Health Sciences Center.

He’d never smoked and was thrown by the specter of lung cancer. He didn’t stick around once the doctors finished talking. He recalls: “I said, ‘Thank you,’ and ‘I’ll see you,’ and I left.”

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Absorbing the Details

At Dartmouth-Hitchcock Medical Center in New Hampshire, clinicians are working with patients on a Foundation for Informed Medical Decision Making project to learn if videos and other materials help prostate cancer patients better decipher their treatment options.

After the patient is diagnosed—but before treatment is discussed in detail—they receive a package that includes printed materials, a questionnaire, and a video, says Kate Clay, RN, program director for the Center for Shared Decision Making at Dartmouth-Hitchcock.

The video outlines the pros and cons of surgery and radiation, including what research has shown, as well as unanswered questions, Clay says. “The reason prostate cancer is a tough one is there hasn’t ever been a head-to-head clinical trial that compares surgery to radiation.”

The materials don’t use pie charts or bar charts to illustrate treatment risks, Clay says. Instead, they take a more straightforward approach, such as highlighting four people out of a group of 100 to show a percentage risk.

The video also provides patients the gift of time to absorb finer details, Clay says. They can rewind a portion of the video or flip through an accompanying brochure. If they have any questions, they are encouraged to contact someone at the Center for Shared Decision Making.

The education appears to be influential, based on the questionnaires patients complete before and afterward. About one in five changed their preference regarding surgery or radiation after watching the video, according to responses from 250 patients across a two-year time span. Nearly 90 percent said they understood the relative risks and benefits after watching the treatment video.



Willie Stewart better understood his options for lung cancer treatment after a tour of the treatment room and a few conversations with a nurse. Photo by Mike Silva.

Different Learning Styles

Patients don't all process information the same way, Osborne says. And doctors can search for clues. She recounts how one time her own oncologist, likely seeing the blank look on Osborne's face, defaulted to hand gestures to demonstrate the relative risk and benefit of a cancer treatment.

In Stewart's case, visualization also helped him better understand his treatment options. Particularly helpful, he says, was the tour that a nurse gave him of the treatment room, enabling him to sit and chat with the patients. Stewart says that nurse, who chased him down the hallway after he fled the physician's office, explained the treatment recommendations over a series of conversations.

Stewart did agree to try eight weeks of simultaneous radiation and chemotherapy in an effort to stunt the tumor's growth. "They said it might help me and it might not," he says. Without it, Stewart was told he likely wouldn't live much longer than a year.

Nearly four years later, imaging scans show the tumor is still there, but it's much smaller and hasn't spread. The treatment "helped me tremendously," Stewart says. "It's been a blessing really." It's a road, moreover, that Stewart believes he likely would not have traveled if someone hadn't taken the time to shed a little illuminating light.

Read a guest blog from Helen Osborne on how to create a patient notebook to help manage the new information from a cancer diagnosis at www.curetoday.com/blog/guest/patient_notebook. To review the full results of the CURE/NexCura health literacy survey, go to www.curetoday.com/health_literacy_survey.