Five Ways to Take an Active Role in Your Health Care

Experts at Fred Hutch Cancer Center explore the importance of health literacy.

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Fred Hutch Cancer Center's goal is to do more than just provide medical care to every patient. Providers and staff strive to educate patients and give them insights they need to make informed decisions about their care. This is done through a focus on health literacy.

In celebration of Health Literacy Month, Fred Hutch is sharing the ways care teams empower patients to make decisions.

What is health literacy?

Health literacy focuses on two main components. First, it involves a patient, family member or caregiver's ability to find, understand and use health information and services. Second, health literacy focuses on how well health care organizations communicate information that allows patients to make informed decisions.

"We have to tell our patients a lot of complex news, and sometimes it's bad news," said Gentry King, MD, a medical oncologist at Fred Hutch. "It can be hard for patients to navigate through what we're trying to say."

One way King fosters health literacy in his patients is to encourage them to ask questions, rather than wait for patients to speak up. "We often conclude a patient visit by asking patients what questions they have," he said. "Sometimes patients don't ask questions if they don't feel they understand everything we've told them. I bridge that gap by telling them, 'This is what to expect.'"

The health care system and medical terminology can be confusing for patients, but King points out that it can be even more challenging for patients who may not have experience with the U.S. health care system or those for whom English isn't their first language.

"I know for a fact, from my own culture — the Filipino culture — that we are not typically patients who advocate for ourselves," King said. "Now that I'm a doctor, I understand that this might not be the ideal course. What's more meaningful for me is to be able to engage with patients and make

decisions together. And the bedrock for that is health literacy."

How does Fred Hutch help patients feel empowered in their care?

As an organization, Fred Hutch's dedication to health literacy runs deep. In fact, there's an entire team dedicated to advancing initiatives related to fostering collaborative patient care. The Fred Hutch Health Literacy Program publishes nearly 1,000 resources for procedures, diseases and treatments — translated into nine languages, as well as a library of videos.

"We come to work every day to help people meet their treatment goals," said Laura Carr, manager of the Health Literacy Program. "If we can't communicate effectively with patients — or each other — we won't be able to do that."

Since care teams are on the front lines treating patients, Carr's team offers a training program for staff that covers topics like the importance of using clear, straightforward language, how to use the teach-back method, and how to problem-solve for unique communication challenges.

"I had a patient who had challenges reading, and the Health Literacy team suggested I leave appointment information on his voicemail," said patient navigator Andrea Suzuki. "I called him and told him I was going to call back and he shouldn't answer, so I could leave all of his appointment information on his voicemail."

How can patients advocate for themselves?

Patients play a pivotal role in their own care. They know themselves best, and can help guide treatment decisions by advocating for their wants and needs, building a strong foundation with their care team.

"We can develop a really strong partnership between doctor and patient," said King. "I think when you're going through difficult times, you feel like you can get through it because you have your care team as a partner."

Here are a few ways Fred Hutch encourages patients to advocate for themselves:

1. Speak up.

Bring a list of questions and concerns so you don't forget anything. Feeling overwhelmed? Start by sharing what's most important to you so it isn't pushed to the end of the appointment when you've run out of time.

In addition to questions, be sure to let your care team know how you've been feeling, both physically and emotionally. Mention any new symptoms or side effects, no matter how mild.

2. Ask follow-up questions.

Appointments can include a lot of information, so jot down questions in real time, as your care team is sharing details. Then, get all your questions answered before your appointment ends.

It can also be helpful to explain what you've just heard back to your care team. Say something like, "Just to be sure I understand, you're saying…" If something isn't clear, don't hesitate to ask your care team to explain it again or in a different way.

And if you forgot to ask a question or something still doesn't make sense after you leave, reach out to your care team via MyChart or by phone.

3. Share how you like to receive information.

Make sure your care team knows how you prefer to receive information for the topic that you're learning about. Are pictures or physical models helpful? Or perhaps you learn best from video? Also be sure to ask your care team for translation support if you need materials in another language.

"As I got to know my medical oncologist, Dr. Natasha Hunter, she came to learn that I prefer to have as much information as possible as early as possible," said Terri Rau, who was treated for breast cancer at Fred Hutch. "She always gave me very medically detailed explanations about why we were doing what we were doing. It made me feel like although different patients have different communication preferences, Fred Hutch values each patient as part of the team and wants every patient to feel like they have full agency in the decision-making process."

4. Bring a loved one.

Caregivers play such an important support role, and one way they can help is by attending appointments with you. It can be helpful to have a second set of eyes and ears in the room. Ask caregivers to take notes and jot down follow-up items.

5. Request extra support.

If taking an active role in your care feels overwhelming or uncomfortable, Fred Hutch's Social Work and Patient Navigation teams can help. Fred Hutch patients can ask their care team for a referral.

"Everyone can relate to being overwhelmed at a medical appointment or feeling too nervous to ask questions," said Carr. "At the end of the day, the goal of Fred Hutch's health literacy initiatives is to improve the two-way communication that takes place between patients and care teams."

Learn more about how to take an active role in your care.

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