

The key to patient advocacy: resourcefulness



Dr. Jo Anne Earp, left, makes a point during a class she teaches with colleague and fellow patient advocacy expert, Elizabeth French. They co-authored the book *Patient Advocacy for Health Care Quality*.

Long gone are the days when a seriously ill patient had just one doctor, likely one who had known her for most of her life. Today, patients with a serious diagnosis enter a medical world filled with specialists, advanced technology and mountains of information on the Internet.

“People have to navigate really complicated health systems today, especially when coping with a complicated illness like cancer,” says Elizabeth French, MA, associate director of

academic affairs in the Department of Health Behavior and Health Education at the UNC Gillings School of Global Public Health. “It requires huge amounts of resourcefulness.” ▶▶

In addition to pushing for more research, cancer advocates have helped improve the way care is delivered. Patients and families are more involved in decision-making.

— Elizabeth French

Being well informed is one thing. Actually advocating for yourself or a loved one is all together something else. And figuring out how to access the latest treatment, push for safer health care or even learn the terminology for your disease can be exercises in frustration.

“Patients who are newly diagnosed with a serious illness like cancer are scared, vulnerable and often disoriented, and this is the time they also need to pretty quickly learn the ropes of complex medical processes that may also feel dehumanizing,” says French. “But there’s good news, too. In addition to pushing for more research, cancer advocates have helped improve the way care is delivered. Patients and families are more involved in decision-making. Patients often sit on family councils that help hospitals set policy on how care is delivered, so they have an influence that way, too.”

French and Jo Anne Earp, ScD, professor and chair of the Department of Health Behavior and Health Education, teach a graduate level course on patient advocacy. They define patient advocacy as “the wide range of interventions promoting patient-centeredness, patient safety and patient voice in the health care system.”

As Earp and French note in their book, *Patient Advocacy for Health Care Quality* (published by Jones and Bartlett in 2007), a patient advocate can be the patient, a friend or family member, a palliative care provider (such as hospice) or an activist organization that agitates for social change and legislative action.

One prominent advocacy organization is the National Breast Cancer Coalition, which

holds annual weeklong educational programs to train breast cancer advocates in basic science, epidemiology and clinical medicine. Courses also are offered on how to lobby for improved health care. Robert Millikan, PhD, DVM, Barbara Sorenson Hulka Distinguished Professor of epidemiology, has served as an instructor in the program since 1994.

Millikan says that advocates can provide insights into different cultures and contribute to the success of studies by making writ-

ten and oral communication more relevant and understandable.

“The advocates really serve as our eyes and ears, and play an important role in making epidemiological research more responsive to the needs of the communities,” he says, citing the Carolina Breast Cancer Study as an example. That study focuses on the causes of breast cancer in African-American women. The community advisory group helped create a statewide, comprehensive resource directory about breast cancer diagnosis, treatment and support around the state, and also developed a Web site for the study.

Whether an advocate is reminding a provider that her patient is allergic to a particular kind of medication, pushing for redesigned hospital rooms, insisting on a different course of treatment, or lobbying Congress for a new federal law, the goal is the same: greater dignity, safety, access and empowerment for the patient and better communication between patients and their health care providers. ■

— By Kim Gazella

ADVOCACY TIPS

1. Establish a relationship with a primary care provider. This is the provider who knows you over time and knows what “normal health” means for you.
2. Speak up with concerns about your condition. Tell your doctor about your symptoms, and ask for explanations. Don’t be afraid to ask questions!
3. Educate yourself. Go online to learn more about your illness, but be sure to confirm information with your doctor or other reputable sources.
4. Ask a family member or close friend to serve as your advocate if you are being admitted to the hospital. This person can report symptoms, communicate your needs, check your medications and serve as a troubleshooter.

RESOURCES

- Patient Advocate Foundation: www.patientadvocate.org
- Institute for Family-Centered Care: www.familycenteredcare.org
- National Long-term Care Ombudsman Program (will assess and improve situations related to long-term care facilities): www.ltombudsman.org