

> Taking Charge

Empowered patients make their own decisions after diagnosis. By Glenda Fautleroy

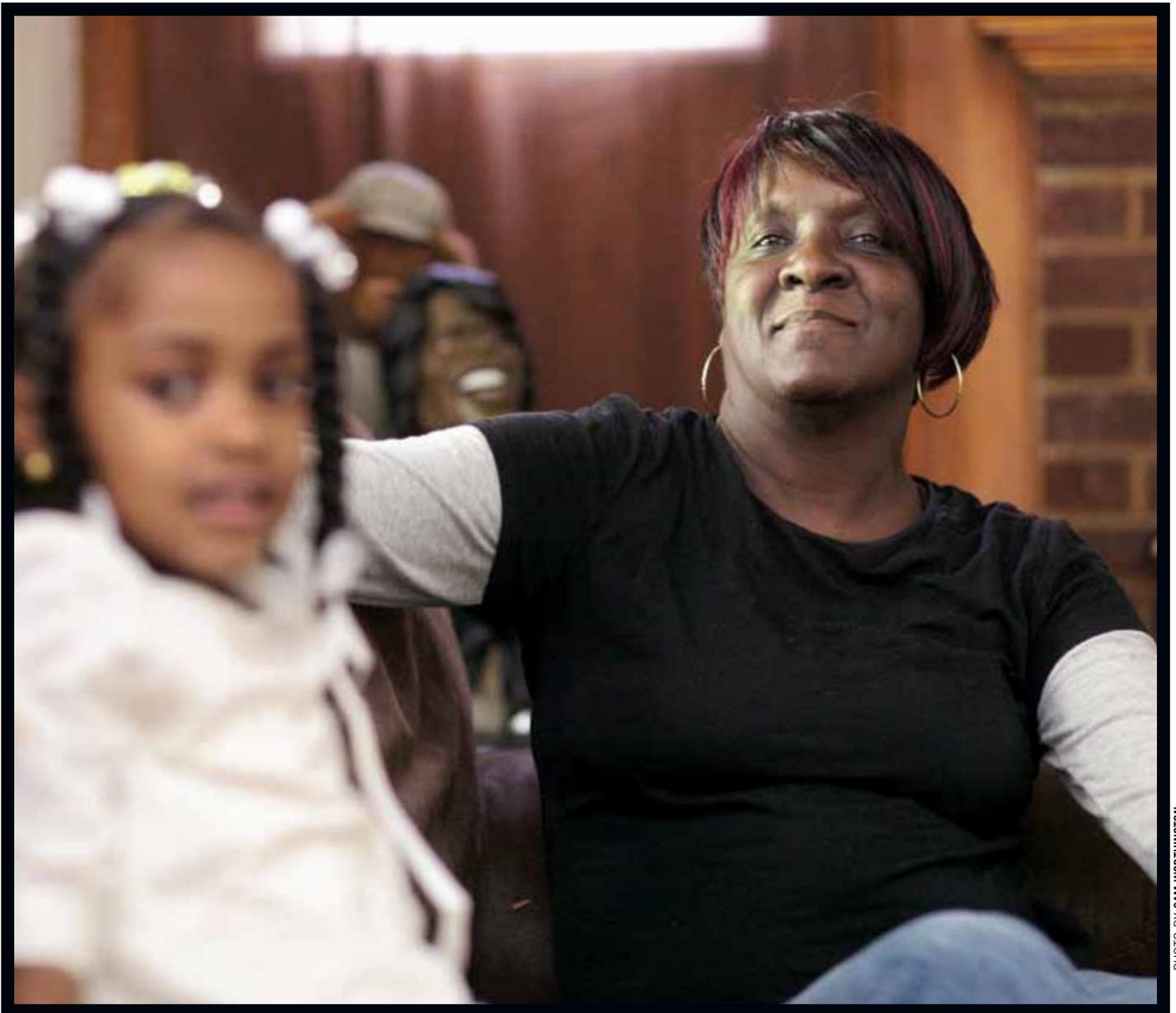


PHOTO BY SAM WORTHINGTON

Although Gwendolyn Otey's three adult children and 10 grandchildren were supportive, she also relied on her cancer center's support group.

Talking Points >

⇒ **PATIENTS CAN TAKE CHARGE** of their health care by preparing a list of questions for their doctors.

⇒ **PATIENTS CAN MANAGE** supporters by telling them what they need—and what they don't.

WHEN THE DOCTOR DELIVERED THE NEWS of her cancer diagnosis last fall, Gwendolyn Otey was in absolute denial.

“When I heard the words ‘lung cancer,’ they just didn’t make sense to me,” Otey says.

Otey, 58, of Richmond, Va., recalls being shocked during the first visit with her oncologist and admits that when doctors said she needed to have a third of her right lung removed, the news was overwhelming.

“Hearing them say what they wanted to do to me, I felt like I was in another world,” she says.

A PATIENT-CENTERED TEAM

As patients like Otey come to terms with their cancer diagnosis, many want to be in charge of their own decision-making but are often too emotionally weighed down to take the reins. Experts say the first step for

their healthcare providers in the decision-making process.

Hackney recommends three websites she says are patient-friendly

and offer evidence-based information that reflect the national standards of treatment: The American Society of Clinical Oncology’s patient site (cancer.net), the National Comprehensive Cancer Network (nccn.com) and the National Cancer Institute (cancer.gov).

“Be wary of where you get health information,” Hackney says. “I tell my patients never to Google their cancer because random searches can pull up websites that may give more alternative and holistic advice that’s not backed by science.”

Hackney’s recommended sites also offer patients “questions to ask your doctor,” which she says are a good starting point for learning more about a diagnosis during the first visits with an oncologist. Hackney

“SOME PEOPLE feel better when they can say, ‘This is my situation, these are the healthcare team members I’ve picked, and this is what we’ve decided to do.’” —MARY JANE MASSIE, MD

patients who want to take charge is to learn about their cancer type.

“As scary as cancer is, [most patients] have time to get the right information in order to make the best decision,” says Mary Helen Hackney, MD, a medical oncologist at Virginia Commonwealth University Massey Cancer Center in Richmond.

In fact, a 2009 review of more than 50 research studies showed that when patients use what are known as “decision aids” to get health options about their conditions, they have an easier time making decisions. Decision aids—pamphlets, videos or websites—that include treatment options with the possible benefits and harms can help patients become more knowledgeable and better prepared to participate with

suggests asking specific questions, including about the cancer type, stage and characteristics, as well as how it is treated and the side effects of the treatment options.

But even when they are prepared with a list of questions, patients often are too overwhelmed or anxious to comprehend the doctor’s answers or ask for clarifications, experts agree.

“In the best setting, patients remember half of what I tell them,” Hackney says. “I suggest the patient bring along a second person, so the patient can focus on the discussion with the doctor and the second person can be the note-taker.”

DIAGNOSIS DISCLOSURE

Once the patient is armed with the accurate

information, a second take-charge approach is to hold off telling family and friends about the diagnosis until there's been enough time to digest it and make decisions.

"Some people feel better when they can say, 'This is my situation, these are the healthcare team members I've picked and this is what we've decided to do,'" says Mary Jane Massie, MD, an attending psychiatrist at Memorial Sloan-Kettering Cancer Center in New York.

"You're letting everyone know that 'I'm not asking you to make my decisions, but I will need your help in other ways later,'" she adds.

And deciding exactly who to tell about the diagnosis is important, too. It's smart for patients to protect themselves as they go through decision-making and only tell people who will be helpful, Massie says.

"Think through carefully who you want to tell, and when and why," Massie says. "Telling a lot of people about your diagnosis can sometimes bring a ton of opinions from people who have little health experience or whose last contact with the healthcare community was 20 years ago."

When word of the diagnosis does spread, well-meaning family and friends who want to help or



NETWORKING

Coping with a new cancer diagnosis and subsequent treatment is a life-changing event. The following techniques can help patients build a balanced network of support as they proceed:

RELY ON A GATEKEEPER. Patients should ask someone to help protect their privacy as they come to terms with their condition. This person can share messages with family and friends and tell them that the patient will be in touch.

SEE A SOCIAL WORKER. Oncology social workers can help patients with transportation and financial resources, as well as disability and insurance issues. They also provide emotional support and help patients

communicate effectively with their medical team.

TRY CREATIVE THERAPY. Many centers offer art and music therapy sessions to relieve the stress of the cancer experience. Creative therapy can help patients relax and change their mood.

GO VIRTUAL. Locate online communities that help patients who are unable to make the trip to hospital group meetings, such as

WhatNext (whatnext.com), developed in part with the American Cancer Society.

PRACTICE SELF-CARE. Massage, meditation or warm baths can offer a necessary distraction that patients can control. Kay Guidry, a social worker at the Indiana University Melvin and Bren Simon Cancer Center in Indianapolis, also encourages patients to make a "worry box" where "they write down every day what they're worried about, put it in the box and leave it there." —GF

offer advice can quickly overwhelm many patients. To manage a team of supporters, a continual take-charge attitude is a must.

MANAGING SUPPORTERS

As calls pour in, be sure to send the right message to supporters.

“You want to say that you appreciate them but will be in touch when you need their help,” says Kay Guidry, an outpatient oncology social worker at the Indiana University Melvin and Bren Simon Cancer Center in Indianapolis. “People feel good about helping, so designate a best friend or close family member [who is a good administrator] to organize your team.”

Marking a calendar of days when help will be needed and days when privacy is wanted will be key to managing supporters. Ask the designated team leader to assign days for family and friends to visit or deliver meals, provide transportation to treatment appointments, care for children or the household, and run errands.

And while some patients tend to feel guilty about

only
on the web:

Tips for developing a strategy to manage a support team from the point of diagnosis.

curetoday.com/blogs/kathylatour/team

phone, don't feel I'm ignoring you, it's just that I'm in one of my moods and will call you later,” Otey says.

“Your family and friends should understand that you need space,” she adds. “Just be honest and tell them in a nice way that you need some time to yourself.”

A good way patients can protect themselves from an onslaught of phone calls or emails is to have someone send out occasional updates by way of a group email or through social media, Massie says. Or, many patients find it therapeutic to personally compose these messages in the form of a short journal or blog.

But Guidry advises patients to restrict these messages to people who make the most impact on their life.

“It's sort of like when you send wedding invitations,” Guidry says. “You don't want to send [them] to people you haven't talked to in 10 years.”

Although a huge circle of family and friends, including three adult children and 10 grandchildren, surrounds Otey, she says she depends a great deal on the weekly support group sessions at her cancer center.

“YOUR FAMILY and friends should understand that you need space. Just be honest and tell them in a nice way **that you need some time to yourself.**” — GWENDOLYN OTEY

limiting visits or calls from well-wishers, Guidry says to ignore those impulses.

“This is the patient's time,” Guidry says. “If there's any time in your life that you can be very blunt and matter-of-fact, this is it.”

Otey says her phone rang constantly when news of her diagnosis spread, and the calls initially made her angry and depressed. She soon, however, developed a strategy to cope.

“I began to tell everyone that if I don't answer my

“When I go to the weekly support group meetings and talk about myself, I come out feeling like a new person,” Otey says. “When I meet anyone else who has cancer, I tell them to try the support group because I feel like it saves my life.”

Support groups offer patients an ability to interact with other people who have some of the same feelings and symptoms they're experiencing, Guidry says. “You can't get that from people you love if they haven't lived with cancer.” □