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THE NEW MEDICAL ADVOCATES

BY ELIZABETH POPE

very patient, in a perfect world, could just focus on getting well and not expend precious energy on figuring out a complex healthcare system. "Medicine today is a team sport that requires the care of multiple specialists, different departments, and lots of tests," says James Merlino, chief experience officer of the Cleveland Clinic. That's why so-called patient advocates or navigators are among the newest members of the healthcare team, working for hospitals, healthcare organizations, or private clients. Many advocates have a background in nursing, social work, case management, or law. But friends or loved ones can serve as advocates, too, says Merlino. "Imagine if every patient had someone with them to ask questions and track information—or just remind providers to wash their hands when they come into your room," he says. "That helps us do a better job."

A savvy helper. Cleveland Clinic, like many large hospitals, assigns a navigator to its more complex or critical cases and to assist underserved patients from low-income communities. In September 2010, April Peters was diagnosed with breast cancer and lymphoma. "I was terrified. I had two kinds of cancer at the same time," says Peters, 50, of East Cleveland. Married and a mother of four, she had insufficient insurance, money worries, and transportation problems as she confronted a brutal regimen of radiation, chemotherapy, and a bone-marrow transplant.

Then Mary Anne Ott, a patient navigator at Cleveland Clinic's Taussig Cancer Institute, stepped in to help. Ott's patients are referred through free screenings, clinics, and other local partner organizations. Ott accompanied Peters on medical appointments, helped restore her Medicaid insurance, and aided her in applying for prescription drug assistance and Social Security disability benefits. She also connected Peters to support groups and free resources as she confronted a brutal regimen of radiation, chemotherapy, and a bone-marrow transplant.

Though advocates employed by hospitals can play a valuable role, they also can have a built-in conflict of interest, cautions Lisa McGiffert, director of Consumers Union's Safe Patient Project. In a dispute, she says, they "aren't necessarily working for you. That doesn't mean that they can't be helpful, but it means you are not their primary client." Private-hire advocates can play a broad or specialized role. Some will research diseases, find doctors, manage paperwork, and help patients better understand their conditions. Others focus on one area such as insurance disputes or legal matters. Hourly fees range from about $60 to over $250. As yet, the emerging field has no official licensing and credentialing requirements, but the National Association of Healthcare Advocacy Consultants is developing professional standards and best practices. A directory is available at www.nahac.com.

Patient advocate Mary Aime'-Juedes, a registered nurse in Scottsdale, Ariz., sees her role as helping clients "get the best healthcare outcome possible." Recently, she assisted a 63-year-old man with asthma and immune deficiencies who underwent surgery that resulted in the removal of his spleen and part of his pancreas. Aime'-Juedes collected and reviewed medical records from her client's 11 treating physicians, accompanied him on appointments, regularly visited the hospital during his week-long stay, returned when he was readmitted with an infection, and provided continuous support in between. Says the patient, who asked to remain anonymous, "Mary knew exactly what to ask the doctors, caught several communications problems, and made sure I got the right tests." At $100 an hour, the bill came to roughly $7,000. "But it was worth every penny," he says.

Insurance companies do not currently reimburse private advocates' fees. "A professional advocate may be great if you can afford it, and as long as you've vetted their background and credentials," says McGiffert, who advises asking for references and inquiring about training and familiarity with cases similar to yours (as well as their outcomes).

If cost is an issue, it's worth asking a friend, family member, or neighbor to accompany you to medical appointments. You'll have an extra set of eyes and ears, and it won't cost you a dime.