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MEDICINE

A New Breed

Professional help is available when navigating a complicated **HEALTH CARE SYSTEM.**

LESS THAN TWO WEEKS BEFORE starting radiation for Stage I breast cancer, a patient wanted to know how radiation on the tumor in her left breast could affect her heart over the long term. Afraid to offend her doctor by seeking a second opinion, she turned to Vienna, Va.-based Patient Navigator for help.

In one day, Dr. Karen Zorrilla, the company's medical director, found relevant journal articles and a specialist who was able to answer the woman's questions and give her peace of mind.

Zorrilla is a patient advocate, a new breed of consultant helping consumers navigate the labyrinthine U.S. health care system.

"It's draining enough to be sick," says Elisabeth Russell, president and founder of Patient Navigator, "let alone having to deal with the health care delivery system and all of its vagaries and complications."

These consultants, also known as medical advocates, patient navigators and the umbrella term *health care advocates*, offer a range of services. They help patients learn about options by researching diagnoses and treatments. Many assist in communication among physicians and patients. They help clients define health care goals, set agendas for doctor visits and shape expectations.

Their work styles vary. Many patient advocates accompany clients to appointments and hospital visits; others may consult strictly by phone. Some help patients in developing questions to ask doctors and in understanding the answers. Advocates



may gather records and create a multiyear summary of a patient's medical history to help physicians get a snapshot of salient points. While patient advocates employed by hospitals or insurers aim to mitigate risk or cut costs, independent or private advocates answer only to their clients: the patients.

Squeezed for time, intimidated by doctors and not feeling their best, patients or their families hire health care advocates and are willing to pay \$60 to \$200 per hour to get the research and advice. Those costs are not covered by insurance.

"The people that we get are very complicated medically," says Joanna Smith, who founded the National Association of Healthcare Advocacy Consultants in 2009 and is CEO of Healthcare Liaison, Inc. in Berkeley, Calif. For one client, she coordinates care among 12 specialists and a primary-care doctor who otherwise would not communicate among one another.

"If it were simple, they wouldn't come to an advocate because they wouldn't need us," Smith says.

Unlike medical specialists who deal with one organ or system, health care advocates take a broader view of their clients' needs. Nancy McAfee knew that her sister — who had chronic obstructive-pulmonary disease, high blood pressure, psychiatric complications and was obese — needed help. But McAfee lived in the Rochester, N.Y., area, more than 2,000 miles from her sister in Arizona.

Until McAfee hired a patient advocate, nobody was in control. "Doctors just kept piling on the meds," she says.

McAfee contacted Mary Aimé-Juedes, a patient advocate with RN Patient Advocates of Scottsdale, Ariz. Aimé-Juedes used a computer program to check the 50 medications McAfee's sister was taking. Many of them, Aimé-Juedes discovered, were causing adverse reactions. After talking to seven doctors, she was able to have the medications cut by one-third.

"It was worth it to me to get to the bottom of [the] mess," McAfee says. Sadly, however, the medical problems were ultimately too

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MEDICINE

severe, and McAfee's sister passed away. A patient advocate also can help families who face nerve-racking decisions. As the health of Barbara Porter's father started to decline, Dianne Savastano, founder of Healthassist, based in Manchester-by-the-Sea, Mass., helped smooth communication among her father's health care team, which included family in other parts of the country. "Dianne helped us every step of the way with decisions and getting everybody onboard," Porter says.

Patient advocates can help their clients realize they may have more options than their doctors suggest. When Marshall Krantz learned he had a nodule on his lung, his doctor presumed it was cancerous and urged him to get it removed quickly.

But Smith, his health care advocate, told him he didn't need to rush into surgery and could get a second opinion. "Patient advocates broaden out your thinking," Krantz says.

After an operation, Krantz learned from nurses that he would have to manage the scheduling and dosage of two pain-killers. He was in no shape to do that, however, so Smith intervened and worked out a regimen with the nurses. "She could speak their language and translate for us," Krantz says.

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Finding an Advocate

Before hiring a health care advocate, you'll want to make sure the person's background fits your needs. Some questions to ask:

- Have you handled cases like mine before?
- What would you typically do for someone in my situation?
- What is your background and training?
- How long will it take to perform the services I need?
- What do you charge? How do you charge?
- Do you have references?
- Do you provide written reports?
- What are your hours?
- How do you communicate with clients?

To find patient advocates in your area, check out these directories:

- National Association of Healthcare Advocacy Consultants (www.nahac.memberlodge.com/directory)
- AdvoConnection (www.advoconnection.com)

For Gail Wais, the presence of Aimé-Juedes, her patient advocate, means that doctors are more willing to look over her complicated medical history and share their thoughts.

"They stand at attention while she's there," says Wais, whose swollen face has puzzled doctors. Aimé-Juedes knows Wais' history well enough that she may say to the doctor, "That's been tried. What can you bring to the table that we haven't seen yet?"

Patient advocates help empower their clients to become more savvy health care consumers. When Susan Kaplovitz was told about a type of brain surgery that would reduce the symptoms of Parkinson's disease,

*"It's **DRAINING ENOUGH** to be sick, let alone having to deal with the health care delivery system."*

she and Savastano researched opportunities for the procedure in her area. Savastano encouraged Kaplovitz to pay attention to her comfort level with each team and not to devalue intangibles, like a warm personality. Newly empowered, Kaplovitz realized she sought both competence and accessibility, which made it easy to whittle the list to three doctors.

After peppering teams at the medical centers with questions, Kaplovitz ultimately chose an institution that offered the best aftercare, including an on-site support group, access to a physical therapy program for Parkinson's patients and specialized nutrition counseling. By the time of her surgery, "I was no longer afraid," Kaplovitz says. "I knew enough."

Patient advocates can help their clients solve medical mysteries because they can spend more time on research than most primary-care physicians. When Aimé-Juedes met Bert Winemiller, she wondered if he had a respiratory problem. He had been coughing and wheezing for five years. A primary-care doctor ran respiratory tests and told him he was weeks away from dying because his lungs were delivering barely enough oxygen to keep him alive.


When Aimé-Juedes examined his medical records, she discovered that a heart-function indicator had risen over time. Yet five years later, Winemiller still was taking drugs for cardiomyopathy based on

the initial low number in 2006. A side effect of those medications was respiratory problems.

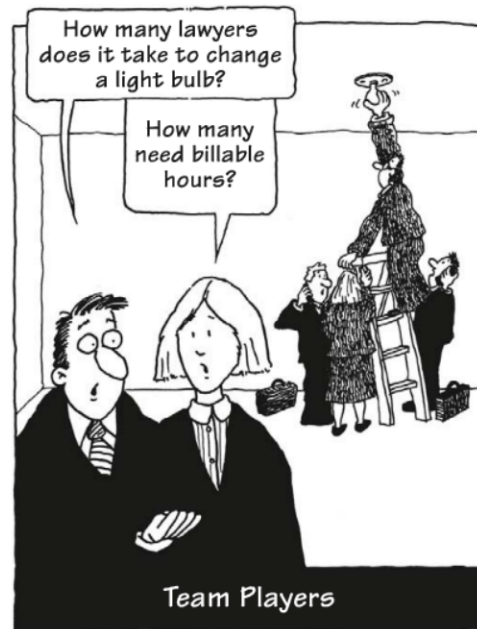
Tests confirmed he never had cardiomyopathy. A cardiologist told him to stop taking the heart medications. His respiratory problems vanished. "Fortunately this misdiagnosis was caught," says Winemiller,

"and I stopped taking the medications that I never needed in the first place."

He considers himself lucky to have met Aimé-Juedes.

"Mary saved my life." 

SANDRA YIN is a freelance writer based in Rockville, Md. She has written for many publications, including *The New York Times* and *The Chronicle of Higher Education*.



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