

# The Columbus Dispatch

## Patients turn to private advocates to navigate medical system

Written by: Encarnacion Pyle, August 3, 2015

After hearing that she needed to see a breast surgeon immediately, Christina Rose had trouble concentrating on anything else her radiologist said.

All she could think about was her sister's recent cancer diagnosis and double mastectomy.

"It was all so surreal," said Rose, 49, of Lexington in northern Ohio. "I was alone in the room; I wasn't sure what the doctor had told me or what questions I should ask."

Desperate for guidance, she turned to a friend, Dr. Annette Ticoras, an internist who had left her practice to raise her three children.

"She was the level-headed, knowledgeable and patient person that navigated me through the devastating medical jargon, expected and unexpected procedures and doctor visits," Rose said. "She was the calm in my storm."

Ticoras, who lives in Westerville, said that experience and others like it, including advocating for her son who has diabetes, made her realize she wanted to join the small but growing field of private-patient advocates. She helped Rose three years ago at no charge, long before she even knew she could make a living as an advocate.

"I wanted to use my medical degree while educating and empowering people," the 50-year-old Ticoras said. "When people can understand their health situation better, it becomes less scary and more sobering. There's power in knowledge."

As medical care continues to escalate in scope and complexity, doctors and nurses have less time to have meaningful discussions with patients, said Trisha Torrey, founder of the Alliance of Professional Health Advocates. At the same time, patients who often are confused or poorly informed are asked to weigh treatment options and make medical decisions.

"Marcus Welby left the building a long time ago," Torrey said.

Private-patient advocates help navigate the medical system. They might accompany patients on doctor visits, explain diagnoses, research treatments, help buy medical equipment, dispute insurance claims or coordinate medical appointments.

"Their goal is to enhance — not interfere — with their care," Torrey said.



Dr. Annette Ticoras is one of a growing number of private-patient advocates.

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She estimates that there are 200 to 250 patient advocates nationwide. But the field is projected to explode over the next decade as baby boomers age and demand more personalized services, she said.

About 75 percent of current advocates are health-care professionals, including doctors, nurses and social workers. The rest is made up of legal and financial experts, as well as former patients and caregivers attracted to the work by personal experience.

Torrey said she was told in June 2004 that she had a rare form of cancer and wouldn't live past that Christmas unless she immediately started chemotherapy.

The 52-year-old marketing professional sought a second opinion. A few months later, she found out that she didn't have cancer at all. Five years later, she founded the alliance.

Five advocates are listed in the directory for Torrey's group as serving the greater Columbus area. But only Titoras, who launched her business, Guided Patient Services, in February, is in central Ohio.

Not everyone is buying into the new field. Some critics say private navigators are expensive, and that the same services often are provided free at hospitals and doctors' offices.

"I find it alarming and a symptom of a broken system," said Cathy Levine, executive director of the Universal Health Care Action Network of Ohio, a nonprofit advocacy group for universal health care.

She said health-care coordination should not be a profit-making business "when it's what our health-care system should be providing in the first place."

Depending on the services and geographic area, clients are charged \$125 to \$350 an hour, Torrey said. Medicare covers some services, but private health insurance does not.

The concept of patient advocates is not new, said Dr. Electra Paskett, a researcher and director of the division of cancer prevention and control at the Ohio State University Comprehensive Cancer Center.

She said a doctor in Harlem developed the first patient-navigation program in 1990 after an overwhelming number of patients came to him with hopelessly advanced cases of breast cancer. By eliminating barriers, conditions could be diagnosed and treated earlier, Paskett said. It's a concept now embraced at hospital systems nationwide, including at Ohio State, OhioHealth and Mount Carmel in central Ohio.

No two hospitals provide exactly the same services. Some focus on cancer patients; others work with people with all kinds of chronic diseases; and a few link frequent emergency-department users with primary-care doctors.

"If you can get people in for care earlier, that reduces outcomes and saves money," Paskett said.

But unlike the services provided in hospitals that must meet federal regulations, there are no nationally recognized standards for private advocates yet, making some worry about the potential for fraud.

"It's a buyer-beware situation," said Mary Szczepanik, manager of cancer navigation at OhioHealth. "Besides, (private-advocacy service) overlaps what we already do."

Still, the need might outweigh some of the concerns, especially for older adults with complicated medical conditions who don't have family members close by to help out, said Cindy Farson, director of the Central Ohio Area Agency on Aging.

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“Our medical system is getting more complex by the day,” she said. “And I think as long as people know what they’re buying upfront and do their homework to make sure they’re hiring a trustworthy, experienced professional, it’s OK.”

Rose said Ticoras explained the diagnosis, went to several doctor’s appointments with her at the OhioHealth Bing Cancer Center in Columbus and was with her when she got her biopsy results.

That’s when she learned that she didn’t have to have surgery.

“She provided peace of mind through it all. She was my rock,” Rose said.