

## Private patient advocates a growing, yet costly, trend in health care

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Barbara Salata was anxious, couldn't sleep and told her family it felt like she was having a heart attack. The 77-year-old Libertyville woman would forget things and generally "wasn't the mom that we knew," said her son, Bob Salata Jr.

Despite a sleep apnea diagnosis and a sleeping pill prescription, Barbara Salata wasn't getting better.

"It became obvious ... we need to get a new team to look at this differently," her son said. "I needed someone to listen to her. We were desperate to find someone who could find some direction for my mother's health care."

So the family hired a private patient advocate, a growing field of [health care professionals](#). The advocate, Teri Dreher, suggested changing Barbara Salata's medications, which the family says alleviated the most troubling symptoms. Dreher worked six months to find a new team of doctors for Salata, who said she now feels more like herself.

Her family credits the changes to Dreher's fresh perspective and her time managing Salata's care.

"It was a service I wasn't even aware was available," Barbara Salata said.

That's because private patient advocacy remains relatively uncommon, said Trisha Torrey, founder of the Alliance of Professional Health

Advocates.

Private patient advocates are not affiliated with hospitals or doctors. Instead they work as private consultants for patients and help manage health needs. Services vary from attending doctor visits, researching medical treatments and helping with medical equipment purchases to handling insurance claims, disputing hospital bills and scheduling appointments.

Advocates say they fill a gap in the health care system by making sure patients - or, as they call them, clients - are educated. They say their involvement relieves stress, especially for those dealing with serious or chronic illness, and that their vigilance and expertise can avert medical errors.

Others point out that many hospitals already offer patient advocates and that the benefits of a private advocate go only to those who can afford to pay. Depending on the advocate and the services, clients can expect to pay a private advocate \$75 to \$300 an hour, Torrey said.

And despite college certification programs, the budding industry has yet to establish an accreditation process - something those in the field say is in the works but still a ways off.

The idea of a patient advocate is not new, said Ronald Wyatt, medical director in the Division of Health Improvement at The Joint Commission, a suburban Oakbrook Terrace nonprofit that certifies hospitals and other [health care](#) organizations across the country.

Typically, though, an advocate is simply a family member or friend who acts as another set of eyes to catch errors and speak on behalf of the patient, Wyatt said. It's a relationship that benefits the sick person and the hospital, he said. "You save lives."

Professional advocates say not everyone has a friend or relative to lean on, and it can be hard for someone who's sick to manage care for themselves.

While many hospitals have patient advocate-type positions, Torrey said they ultimately work for the hospital, not the patient. "An advocate has to have allegiance to whoever is writing the paycheck," she said.

Torrey estimates there are about 250 private patient advocates across the country. Often they're former nurses or have other clinical experience. Eight in the Chicago area are registered with a directory managed by her organization - one of the field's three professional associations.

Torrey founded the Alliance of Professional Health Advocates after her own brush with medical dissatisfaction. In 2004, at age 52, she was misdiagnosed with a form of terminal cancer and given two months to live. A few months later, she discovered the doctors were wrong.

"Along the way I ran into every problem you can imagine ... arrogant doctors, misfiled test results, bad pathology," she said.

Dreher, 59, of Libertyville, worked as a nurse for more than 30 years before she started her company, North Shore Patient Advocates, in 2011. After a medical scare with a family member while on vacation, Dreher said she realized that patient advocacy was lacking. "What do people do who don't have a nurse in the family? That was an epiphany of sorts. Most patients aren't educated enough."

Dreher, who said her business - which includes three other advocates - is taking off, said her expertise "is keeping really sick patients in their homes as long as possible."

One case involved 46-year-old Christopher Ruddy of suburban Crystal

Lake, who was paralyzed from the chest down after a fall in his kitchen broke his neck. His sister, Lora Skeens, 54, said the family hired Dreher so they could bring their brother home. Until December, Ruddy had moved between hospitals and rehabilitation centers since his November 2013 accident, Skeens said.

"We really wanted to bring him home," she said. "We just didn't think we knew enough to get him home on our own."

Before Ruddy's homecoming, Dreher lined up nurses and therapists for home visits and ordered medical equipment and supplies. She conducted interviews with caregivers, worked with the insurance company and coordinated with Ruddy's doctors.

When the insurance company approved the wrong kind of bed, Dreher called and straightened it out, Skeens said. "She knew just what to say."

Embarking on her brother's return without an advocate "would have been a mess," Skeens said.

Dreher said she also hears a lot from children of aging parents. They hire her if they live far from their parents or simply need help managing their parents' care, like the Salatas.

It was Dreher who suggested the change to Barbara Salata's sleeping medication, the family said.

Dreher helped the family hire a new team of doctors, the medication issues got sorted out, a thyroid surgery that had been put off was scheduled, and Salata vastly improved, the family said.

"We basically wiped the slate clean," Dreher said. "She's a new person now."

Dreher's weekly visits with Salata dwindled to every other week, and now she's mostly an on-call resource for the [family](#). As part of her work, Dreher compiled a document that details Salata's medical history and medications, should she ever need to go to the emergency room or encounter a new doctor. Dreher said she also talked to Salata about her health.

"A lot of times it's very beneficial to have a medical professional show up and sit there for an hour and pay attention to them," Dreher said. "There's a great power in just listening. Modern doctors don't have as much time as they used to."

Often private advocates spread the word about their field in an effort to create awareness and find clients.

Like other private advocates, Cybele Japczyk, 50, of suburban Elmhurst, visits senior centers and residences to tout the importance of advocacy. "I can offer people peace of mind," she said.

Some hospitals point out that they offer similar services.

At Northwestern Memorial Hospital's cancer center, nurse navigators are available for patients with breast, lung and gastrointestinal cancers. Lynn Galuska Elsen, a nurse navigator for breast cancer patients, said she'll explain pathology results, guide patients through chemotherapy, schedule appointments and offer advice on how to talk about their diagnosis, among other things. Hospital spokesman Bret Coons said that while navigators are unique to the oncology department, there are other resources for patients at Northwestern.

The University of Chicago Medical Center has patient advocates working in the emergency room and in the general pediatric and cardiology units, said Kimberly Hobson, an administrator who oversees

the advocates.

Though advocates have existed since 2005, the role has evolved and now focuses on educating patients on the importance of a primary care physician, Hobson said. Advocates will schedule appointments and follow up after discharge from the hospital to make sure the patient saw a doctor, she said.

Some predict that roles like these in hospitals will expand, in part because the Affordable Care Act shifts how hospitals receive Medicare reimbursements, focusing more on outcomes and the patient experience, said Pam Brown, president of the American Nurses Association Illinois.

"We're seeing the beginnings of that," Brown said. "Right now, the patient advocate is hired by people who can afford to hire them. The system needs to build that kind of advocacy and coordinated care for everybody."

That might take an overhaul of the way medicine is practiced, said Bernard Hammes, director of medical humanities at Gundersen Health System in La Crosse, Wis., and editor of the book "Having Your Own Say: Getting the Right Care When It Matters Most."

It's the difference between "treating the disease versus treating the person," he said. Hammes helped develop a training program that teaches nurses, social workers and others to focus more on the individual. That's part of the goal of patient advocacy, he said.

Wyatt said that without an accreditation system in place, those hiring advocates should make sure they have completed a certification program, understand the health system and are skilled communicators.

Maryellen Jachimowski, of Naperville, Ill., executive director of the

National Association of Healthcare Advocacy Consultants, works with Dreher. She said that once an accreditation process is in place, and when there are more programs at universities, public awareness and trust of private advocacy will grow.

"They begin to realize they could really use someone to help them make better decisions," she said. "I think they realize it's a godsend."

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