

For when a doctor and a nurse just aren't enough

Boston Globe
5/1/06

The most valuable asset for coping with today's medical system may be an adult family member — preferably one who is well educated, tactful, feisty, and unemployed.

It's helpful to have someone at your bedside in the hospital to make sure overworked nurses notice if your vital signs are going downhill or to ensure that the right medications are given at the right time. It's good to have someone who can get on the Web and research your disease. And it's important to have someone to take notes during doctor visits and ask the questions you forget.

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JACK GALLAGHER

Extra help in time of need

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body that oversees or licenses patient advocates, just some people, companies, and, now, colleges that see a need.

So far, the only school that offers a master's degree in patient advocacy is Sarah Lawrence College in Bronxville, N.Y. At the University of Wisconsin Law School, criminal defense lawyer Meg Gaines, a former ovarian cancer patient, has started the Center for Patient Partnerships to train doctors, nurses, lawyers, and others to help patients research their diseases, find doctors for second opinions, and get insurance coverage. And at the University of North Carolina at Chapel Hill, Jo Anne Karp is creating a set of courses to teach patient advocacy as a career.

The very idea that patients would need an outsider to lobby for them inside a hospital is anathema to many doctors and nurses, who feel passionately that they are already advocates for patients, doing their best to get patients the care they need.

Moreover, many hospitals actually have staff members hired specifically to be patient advocates — folks

who try to straighten out miscommunications between families and doctors and field complaints about bad food, parking, and the like. Massachusetts General Hospital, for instance, has three such advocates. Still, in some situations, there is a need for yet another layer of patient advocacy.

Dr. Jeffrey Biller

If you're in the hospital, and want more-constant monitoring than staff nurses can readily provide, you might consider hiring a private-duty nurse, said Diana Mason, editor-in-chief of the American Journal of Nursing. She hired one recently for the first 24 hours after her sister-in-law had surgery.

But since many of us don't have the perfect family member handy, so-called patient advocates are eagerly leaping into the breach.

Some advocates have minimal medical training; others are nurses and doctors. Some charge nothing; others thousands of dollars. Some advocates might help save your life; others may complicate patient-doctor communication.

JUDY FOREMAN

Health Sense

It's so early in the life of this new profession that it's not entirely clear what an advocate is or how to judge whether you've found a good one. There is no regulatory

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The nurse acted as a "surveillance system," Mason said, frequently checking blood pressure, watching for bleeding, and generally making sure that the sister-in-law did not become a case of "failure to rescue" — someone who deteriorated or even died because early signs of problems were not addressed.

Hospitals often have registries of private-duty nurses to choose from, and some staff nurses are grateful for an extra pair of eyes and ears, Mason said. Insurers won't pay but if you can afford it, the cost — \$250 a day in Mason's case — may be worth the peace of mind and a chance for family members to get some sleep. If a fully trained nurse is more than you need, you can also hire a "sitter" to keep an eye on a patient, who might be in danger of pulling out tubes or falling out of bed.

In other situations, what you may need is a doctor willing to dig into the research your regular doctor may not know about. There aren't many of these folks around — yet — but one of the pioneers is Dr. Gwendolyn Stritter, who runs a telephone-based advocacy practice in the San Francisco Bay area.

Stritter, an anesthesiologist, got fed up with the fast-paced practice she had been in and branched out five years ago into clinical advocacy. She charges \$300 for an initial two-hour appointment, then a sliding scale after that. Most of her clients are cancer patients. She reviews their medical records, combs six to eight online physician databases to find the latest research, then talks to the researchers who've done the studies. She also attends major cancer conferences with her patients in mind.

Carolyn Greenspon, 37, a Newton social worker and mother of two, was also happy to have used a patient advocate when her 4-year old son became sick last summer.

"I am a pretty good advocate myself," Greenspon said. But her son had awakened hysterical after a colonoscopy under general anesthesia. (Agitation is common in children when anesthesia wears off.) When he needed a second one, Greenspon begged the doctors and nurses to sedate him better after anesthesia. She felt her efforts failed when her son became hysterical again.

She then turned to PinnacleCare, a service based in Baltimore that charges as much as \$15,000 for an initiation fee plus a \$10,000 annual fee for a range of services for a family. Pinnacle's advocate, Teresa Lepore, said she got the chief of pediatric anesthesiology to make sure "everyone at the hospital knew this was important."

From Greenspon's point of view, it worked — the nurses carefully managed her son's medication and he did not become hysterical after the third colonoscopy.

But the boy's physician, Dr. Jeffrey Biller, a pediatric gastroenterologist at Massachusetts General Hospital, was less thrilled. The multiple calls from PinnacleCare personnel put an extra burden on his office staff, he said. "Putting a third party in who is not directly involved in patient care actually complicated the situation and made it more difficult."

Bottom line? If you've got a Wonder Woman, or Wonder Man, to help you get what you need from the medical system, count your blessings. If not, consider hiring a private patient advocate. There's a chance that adding yet another person to the mix may complicate your communication with nurses and doctors. But it could also help get you the care you need.

Judy Foreman is a freelance columnist who can be contacted at foreman@globe.com.