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BUSINESS SECTION

PATIENT MONEY

After a Diagnosis, Someone to Help Point the Way

By LESLEY ALDERMAN

WHEN Kathleen Henry's uncle was told he had bladder cancer in May, she knew she needed help. Even though Ms. Henry has a nursing degree, she worried about deciphering treatment options and picking the best hospital for her uncle's care.

So Ms. Henry hired Betty Long, RN, a registered nurse, patient advocate and founder of Guardian Nurses Health-care Advocates in suburban Philadelphia, to help her and her uncle make crucial decisions.



Tim Shaffer for The New York Times
Thomas Murray, who has bladder cancer, with Betty Long, RN, a patient advocate, who helped explain his treatment options. "I would have been stumped without her," Mr. Murray said. "They ought to call her a guardian angel."

Ms. Long accompanied her uncle, Thomas Murray, who is 69 and has no children, on office visits and explained the various treatments his doctors recommended. "I would have been stumped without her," Mr. Murray said. "They ought to call her a guardian angel."

These days, even a person well versed in medical lingo can become overwhelmed by the complexity of the health care system. That is why many patients and their families who can afford it are turning to patient advocates for help. These professionals, who often have nursing or health

care experience, can help a patient research treatment plans, sort out insurance claims and even accompany a patient on doctor's visits. They can frequently open doors to specialists that a patient may not have access to.

Patient advocates have been around for decades, but in the last few years the profession has gained more momentum and acceptance, said Laura Weil, director of the 30-year-old Health Advocacy Program at Sarah Lawrence College in Bronxville, N.Y. "Now everyone seems to agree that you need help navigating a fragmented and technical health care system that is not always friendly," Ms. Weil said.

Indeed, some lawmakers working on health care legislation in Washington have argued that improving the coordination of care would be a way to improve medical care and reduce unnecessary, costly treatments and procedures.

Although there are no firm statistics on the number of patient advocates in this country, or the number of people who are using their services, U.S. News & World Report and CareerBuilder.com recently put patient advocates on their list of hot growth careers.

Many employers, large and small, are also adding patient advocacy to their benefit offerings.

Hewitt Associates, a benefits consulting firm, has helped employers and their workers solve billing and claim problems for a decade. But this year the firm added a clinical advocacy service, which allows employees to call a hotline staffed by nurses and doctors to ask for medical guidance.

"Every single participant who contacts us is angry and stressed out after having tried to deal with the health care system," says Michelle Olef, an advocacy delivery leader for Hewitt. "More and more we were hearing confusion about clinical issues, as well as standard claim issues."

Mr. Murray, a retired Pennsylvania school teacher, did not have access to such an employer-based service. He is on Medicare, with secondary insurance through the state's public school employees' retirement system.

He and Ms. Henry are paying Ms. Long \$200 an hour, out of pocket, for her services. Medicare does not reimburse patient advocate fees, and neither do most commercial insurance plans.

"It sounds like a lot of money, but Betty got us in to see the best doctors in the field and she helped us pick a treatment plan that suited my uncle's needs," Ms. Henry said. "Even if we spend \$1,000 over all, it will be worth every penny." If you want to hire an advocate to help you deal with a serious medical condition, there are a variety of ways to find one.

If money is a concern – and when is it not, with health care? – you could start by contacting the Patient Advocate Foundation (800-532-5274; www.patientadvocate.org), a nonprofit organization based in Newport News, VA.

Their services are free, but they tend to focus more on helping people get access to care or on wrangling insurers, rather than figuring out what medical treatment is best for an individual, said Erin Moaratty, chief special projects officer at the foundation.

If you have employee benefits, call your company's human resource department and ask if they offer patient or health advocate services. If they don't, suggest that they should, and tell them it won't cost them much to do so.

"The average large company spends about \$35 per employee per month in administrative fees alone," said Tom Billet, a senior consultant at Watson Wyatt benefits consulting firm. "Advocacy services cost just \$1 per employee per month."

If you, or the patient, is already in the hospital and frustrated or confused by treatment or medication options, ask whether there is a patient advocate or patient representative on staff.

"A hospital advocate can facilitate the flow of information," said Ms. Weil, who worked as an advocate in New York area hospitals for 20 years. "They can be the point person who can access anyone in the institution for you."

Just bear in mind, Ms. Weil cautioned, that an advocate paid by your company or employed by a hospital may have to represent competing objectives. "Know the agenda of the person who is helping you," she said.

A hospital's own advocate, for instance, may not be allowed to suggest another institution or physician where you might find better expertise for your particular medical condition. If you want to be certain that an advocate has your best interests in mind, be prepared to hire one independently – and to pay out of pocket for their services. Expect to pay either an hourly rate of \$150 to \$200 or a flat fee for a specific service.

According to Kevin Flynn, the president of HealthCare Advocates, a for-profit company based in Philadelphia, his clients pay flat fees of \$150 for a physician referral to \$400 or so for research on treatment options.

How can you find an advocate for hire? Since there is no organization that keeps a central database on the profession, you will have to start by asking around for referrals. If you think your issue does not warrant an in-person meeting, you may be able to use a firm like HealthCare Advocates, which helps clients all over the country solve problems via the phone.

If you want someone to go on visits with you, as Ms. Long did for Mr. Murray, search for a local company or individual on the Internet.

Before you pay anyone a cent, though, ask some pointed questions. Find out what the advocate's credentials are and ask for references. Then talk money: find out how long they think it will take to resolve your problem and what the cost might total. Ask them for a written estimate, as well.

Finally, make sure they have the expertise necessary to be the advocate you need. An advocate may come with glowing references and stellar credentials, but if they don't have any experience dealing with your illness or concern, you both may be wasting your time.

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Thomas Murray, who was diagnosed with bladder cancer, with Betty Long, RN, a patient advocate.