

For Your Own Good

Health care advocates take center stage.

By Kathryn Levy Feldman

When 79-year-old Ventnor resident Mollie Rosen lost her life partner, she had a hard time recuperating from what she thought were physical symptoms related to grief. "I was lying around a lot, but I thought my lack of energy was just part of the mourning process," she says. Just to be sure, she made an appointment with her local cardiologist — and was amazed to discover she needed valve replacement surgery. She found herself questioning the diagnosis, frightened by the possibility of surgery. "I was overwhelmed, very anxious and wanted to be sure I was doing the right thing," she explains.

Enter Guardian Nurses, a Blue Bell-based patient advocacy company that was recommended to Rosen by a friend. Founded by Betty Long, a registered nurse, Guardian Nurses employs registered nurses to help people navigate their way through the health care system. Rosen hired Guardian Nurses to help facilitate her admission to Penn Presbyterian Medical Center in Philadelphia where, after additional diagnostic testing, the surgery was successfully performed. "We remained engaged throughout her stay, making sure she was getting the care she needed, coordinating physician consults, facilitating her transfer to cardiac rehab and eventually to home," says Long. "They were great and exactly what I needed," recalls Rosen.

There is no denying that our health care system is a maze of specialists, treatment options and insurance providers. Even those who consider themselves educated consumers find it difficult to keep up with the latest advances and may find themselves wondering if they (or a loved one) are receiving the best care. Guardian Nurses is but one of the growing number of patient advocate companies that help individuals find their way through the labyrinth, advising them on everything from selecting a doctor, long-term care facility or treatment plans, to resolving insurance disputes, billing and claims.

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Of course, not everyone feels they need the services of a professional patient advocate, but it is important to realize that not all patient advocates offer the same services. The two companies profiled here provide very different methods of “hand-holding,” one literal and one figurative. Neither is right, wrong or even necessary. But both grew out of their respective founders’ personal experiences dealing with their own medical situations.

From Victim to Advocate

When Kevin Flynn, founder and president of Healthcare Advocates, Inc., was a sophomore at the University of Pennsylvania, he sustained a life-threatening head injury. “I was walking on the sidewalk and a drunk driver hit me,” he says matter-of-factly, some 20 years later. “I fractured my skull and was supposed to either die or remain in a vegetative state. I am very lucky to be alive.” Flynn spent months in the hospital and months

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more in rehab, re-learning how to live. At some point, his health care insurance maxed out and he was transferred to Medicaid. Miraculously, he was ultimately able to return to school, although still suffering from seizures.

“By this time, I was pretty good at doing medical research. I determined that I had something called temporal lobe epilepsy,” he says. “I knew exactly which specialist I needed to see. The problem was that I knew he wouldn’t treat me once he found out I had Medicaid.” So Flynn “disguised” himself as the quintessentially upscale Penn student, walked into the specialist’s office and told them he had forgotten his student I.D. but was experiencing seizures. Sure enough, he was seen and even scheduled for a series of tests. That’s when Flynn had to confess he was on Medicaid. “I’ll never forget what he said to me, before he threw me out of the office,” Flynn recalls. “He told me he had just lost money on me and that I should never do that to another doctor.”

Undaunted, Flynn tried the next hospital. This time, he was lucky enough to be seen by a doctor who was also doing research on epilepsy. In this case, Medicaid was not a barrier to getting the tests and treatment he needed. The moral of the story, according to Flynn, is to never give up. “I was young, determined and very persistent, but no one was helping me put all the pieces together,” he says. “At some point in my recuperation, I made a promise to myself that no one should have to go through what I did. I founded this company to find a way to make quality health care services accessible and affordable for everyone.”

Flynn started Healthcare Advocates in 1998, after six years overseas doing exploration for an oil company. Living in such primitive locations as the Arctic, Burma and Yemen “got old,” according to Flynn, who moved back to Philadelphia with the sole intention of starting his company. “No one

was doing anything remotely like it,” he reminisces. “I realized it wasn’t just about educating the consumer. I had to convince them they needed me.” After four years of what he calls “guerilla marketing,” he began to make headway. “Individuals, usually those who were mired in the system, jumped on board first,” he says. By 2002, he began signing up companies, who offered his services to their employees.

Today, Healthcare Advocates, Inc. is a national company with a sliding scale of fees and services for individuals as well as corporations. “The fees for individuals can range from \$50 to \$400 per month, depending on the situation,” says Flynn. “Some companies can pay as little as \$2 to \$3 per month per employee.” The services Healthcare Advocates provides to its members include physician referrals, advice on selecting a nursing home, a treatment plan, prescription or dental

plans, and help resolving insurance claims or disputes. On the Healthcare Advocates website, Flynn compares his approach to that of an auto club. “They don’t sell you a car, nor do they fix your car. They simply make your entire driving experience better. Healthcare Advocates doesn’t diagnose you, nor do we treat you. We make your health care experience better.”

One thing Flynn’s organization seems to do very well for its members is cut through red tape. Members who were denied coverage for various reasons often have it reinstated. Others who were billed erroneously have their claims resolved. “Billing errors are very common,” says Flynn. “A doctor’s office will get pre-authorization for a procedure and then bill for it anyway.” One of Flynn’s members was denied a mortgage for an outstanding hospital bill three years prior that his insurance company had neglected to pay until Healthcare Advocates tracked it down. Another had their out-of-pocket expenses for surgery done by an out-of-network surgeon reimbursed because it was deemed to be an emergency. Another, who had no insurance at the time, had his bills for an unexpected hospitalization greatly reduced.

One thing that Flynn’s staff of doctors, lawyers and insurance specialists will not do, however, is accompany you to your doctor’s appointments or check up on your treatment while in the hospital. “We think it sends a mixed message and that the quality of care might be compromised,” he says simply. He advises that you enlist his services “anytime you are going to have any type of procedure that is over \$1,000. Think of us as cheap insurance or a sounding board,” he smiles. “Today, a patient has to fight more and more for themselves. That is often very hard to do when you are not well. And people become very emotional when family members are involved. It’s hard to be your own advocate.”

The Guardian Angel

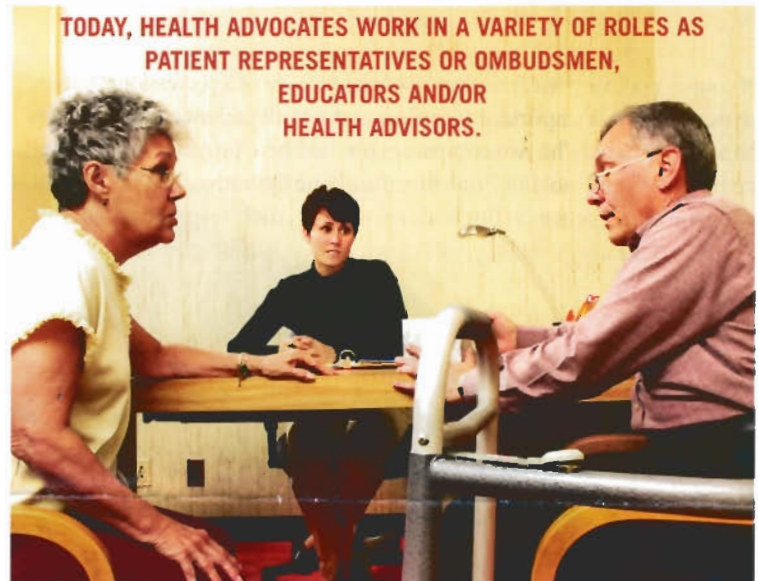
Southwest Philadelphia native Betty Long always wanted to be a sportswriter. That is, until her mother got sick in 1982. “My life changed when my mom got cancer,” the former Temple tennis player notes. “The nurse who took care of her had such an impact on my life that I decided to go into nursing.” Long graduated from Abington Memorial Hospital School of Nursing in 1986 and worked at both Einstein and MCP in critical care until 1994, when she went to work for Siemens doing software consulting. “I found I missed being in a hospital, so I took a part-time job for Tenet as a nursing supervisor and worked the 4 to 12 shift,” she remembers.

It was during this time that she saw, firsthand, the problems that patients, family members and nurses themselves faced on a day-to-day basis. “I remember one situation where a daughter had come to see her mother, only to discover that she hadn’t eaten all day. The nurses on the floor were too busy to do any troubleshooting, so they called me,” she says. “I found out that the mother was scheduled to have a procedure the next day that required she not eat for 24 hours. No one had bothered to tell her daughter.”

When Long’s uncle was diagnosed with a brain aneurysm, she helped her aunt navigate the reams of paperwork and myriad decisions, all the while wondering what people do when they don’t have a relative well-versed in “medicalese.” “I was beginning to conduct my own informal feasibility study by asking patients and their family members if they would hire someone to help them navigate the health system,” she recalls. “Most of them said, ‘yes.’” That was in 1999. It took Long a few more years to figure out how to make money from this service. She formally started Guardian Nurses in 2003, while still working part-time at the hospital and continuing to, as she puts it, “give my services away for free.”

Her first break came in 2005, when the Philadelphia Fraternal Order of Police hired her to provide her services to its members. Since then, Long has signed up other local unions as well as insurance brokers and individuals. She employs a staff of six nurses (“with 11 in the bullpen”) and bills by the hour or the case on an individual basis. “Our consultation fee is \$150 per hour and our standard rate is \$200 per hour, but we discount to patients if we spend more than five hours” on a case, she explains. She also has a client who keeps her on a yearly retainer, “just in case.” “That person really ‘gets’ what a nurse advocate can do for her,” she explains. “In case she needs us, we are available to assist with a hospitalization, an ER visit or a new diagnosis.”

In Long’s seven years of business, she has had only one experience in which a doctor felt “threatened” by her presence in the room. “Most of the time, a doctor is intrigued and also a bit more relaxed, knowing that he can speak freely and a nurse will interpret,” she says. As for assessment of bills, “if we think we can help you, we will take the case,” says Long, who adds that she has had success in sorting through red tape.



“Believe me, the last thing you want to do when you have cancer is get on the phone and deal with an insurance company.”

Health advocacy, as a profession, has been around since at least 1980, when Sarah Lawrence College established the first (and, so far, only) master’s program in the field. According to Marsha Hurst, director of the program from 1996 to 2007, the field itself grew out of the patient rights movement of the 1970s, spurred on by the creation of the first Patient Bill of Rights adopted by the American Health Association in 1972. Early health advocates were more likely to have been rallying for a cause as opposed to an individual, and many disease-specific advocacy groups were formed in organizations that still exist today. There is no doubt, however, that the field is gaining new acceptance as well as recruits.

Today, health advocates work in a variety of roles as patient representatives, ombudsmen, educators and/or health advisors. Many hospitals employ patient advocates to ensure the patient’s medical and health needs are met and to mediate conflict and facilitate positive change. However, according to Healthcare Advocates’ Flynn, it is important to recognize that the role of an in-house patient representative is not to be confused with that of an independent advocate. “You should always remember that the in-house patient advocate is part of the hospital’s risk management team,” he notes.

The final decision as to whether or not you need a patient advocate is an individual as the person making that decision. But regardless of whether or not you ever hire one, it is always good to know that there are people who can help you find your way through the maze.

Guardian Nurses can be reached at 215.836.0260 or on the web at www.guardiannurses.com. Healthcare Advocates, Inc. can be reached at 215.735.7711 or on the web at www.healthcareadvocates.com.

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