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Advocates guide patients through medical morass

By Lini S. Kadaba

PHILADELPHIA - The MRI of Bill Wynn's brain in September revealed a troubling spot—most likely an acoustic neuroma, his doctor explained, which would account for the constant whistling in Wynn's left ear and the drooping on one side of his face.

The specialist recommended immediate surgery to remove the tumor.

Was that his only option? wondered Wynn, 62. Brain surgery is risky, and he could suffer hearing loss.

For help, Wynn turned to Betty Long, one of a burgeoning category of health-care professional: the personal advocate.

Long, a registered nurse, founded Guardian Nurses in Flourtown, Pa., in late 2003 after witnessing the confusion of family members when her uncle suffered a brain aneurysm.

She looked at patients in intensive care, Long said, who came to her relatives' aid, and thought, "What do people do who don't have someone to help them?"

In Wynn's case, Long apprised the Philadelphia detective of a noninvasive treatment known as gammaknife radiation, and suggested he see an expert. She fast-tracked his initial appointment with neurosurgeon David Andrews in November, and provided a cheat sheet of questions.

"You wouldn't think of going into the legal system without a lawyer," Long said. "You wouldn't want to go into the medical system without an advocate. It's so overwhelming."

For a fee, personal advocates navigate the labyrinthine health-care system, identifying specialists, translating doctorese, and negotiating insurance claims.

These medical concierges, often nurses, mostly counsel by phone, though some local firms may accompany patients to appointments.

Hospitals have long had patient advocates on staff. But personal advocates are not beholden to any institution or treatment.

While they do not make medical decisions, advisers lay out choices in plain English.

"This trend ... really highlights the fact that we have a broken system," said Anne Weiss, senior program officer at the Robert Wood Johnson Foundation in Princeton, N.J. More companies are offering the service in their benefit plans, an arrangement they say is a win for everyone. Advocates attempt to find the best doctors for what ails employees, and employers pay for fewer wrong diagnoses and unnecessary procedures.

Advocates can flag potential future problems—by discovering someone’s high blood pressure at a health fair, for instance—and encourage healthy behaviors. And when a pro handles insurance claims or billing errors, workers can focus on their jobs.

“We get a lot of calls where people are lost in the system,” said Marty Rosen, a cofounder of Health Advocate in Plymouth Meeting, Pa. “We’ll make the connection. We know the health-care system, the ins and outs.”

He should. Rosen and his partners are former U.S. Healthcare and Aetna executives. Yes, he sees the irony of having to untangle problems blamed on his former industry. But, he says, “Who better than us?”

Health Advocate, which is contracted by employers nationwide, has seen its list of clients explode from 10 businesses in 2002 to 1,700 today. The company’s services are now accessible to 6 million people, Rosen said.

Large corporations pay a monthly \$1.25 per employee; small outfits, \$4.95 per employee.

“Health Advocate gets people what they’re due,” said Stephanie Capaccio, director of benefits and risk management for Wawa Inc., a client since 2004. “They have clout.”

And the expense to Wawa? Compared with the millions employee health-coverage costs, “it’s peanuts,” she said.

Advocacy providers court employers, but many also have private customers. Healthcare Advocates, a Philadelphia firm with a mix of clients around the country, describes itself as “the auto club of health care.” Services carry flat fees ranging from \$50 to \$400, plus a yearly charge of \$19.95.

“People come in and have a shoe box full of bills,” Kevin Flynn, president, said.

That was what Rachel Taylor Brown faced when she turned to an out-of-network physician for brain surgery. In a crisis, “you’re not thinking ‘it’s out-of-network,’” Brown, 25, said. “You want the best.” Flynn negotiated significantly lower charges, she said.

The niche industry, which emerged in the ‘90s, is too young to have its own professional association—making a count of advocacy companies hard to come by, said Marsha Hurst, director of the Health Advocacy Program at Sarah Lawrence College in Bronxville, N.Y. Anyone can hang out a health-care advocate shingle—cause for caution, she said.

“You don’t have a code of ethics that you can rely on,” said Hurst, who is helping to establish standards.

Traditionally, graduates of Sarah Lawrence’s advocacy program have joined hospitals or nonprofit groups. Now Hurst sees interest in the private sector.

Baby boomers of certain means are used to choices and expect them in health care, she said. They don’t have time to do the research, however. But consumers should be wary, Hurst said. Will an advocate tied to an employer share all options, even costly ones? “Is that really an independent advocate?” she asked.

Perhaps surprisingly, many physicians say they welcome advocates into their offices.

“Advocates are asking very sophisticated questions,” said Mehmet Oz, vice chairman of surgery at New York Presbyterian-Columbia University and coauthor of “You: The Smart Patient,” an irreverent guide to getting the best treatment. “I find that an empowered patient does better.”

Oz said he would recommend an advocate for major procedures and most chronic conditions. “If you

have a hernia repair, I'm not sure it's worth it," he said.

He takes no offense at someone looking over his shoulder, he said, and believes most physicians feel likewise. "This is a very, very nice way to avoid getting sued," he said.

When Bill Wynn faced his scary diagnosis, he called his union's health plan, Law Enforcement Health Benefits, which has a contract with Guardian Nurses at \$132 an hour.

Guardian knows which doctors get better results for particular conditions, and that has saved the plan several million dollars, plan administrator Tom Lamb said.

In one case, he said, Guardian discovered that a faulty hospital machine had slowed a member's recovery after knee surgery, and made sure the health plan was not billed for the extended treatment.

Besides giving Wynn more options, Long, of Guardian Nurses, reminded him of follow-up appointments. "Geez, I felt like my mother was back alive," he said.

On a June day, Wynn broke away from work to go over tests with Andrews, the neurosurgeon. Long was at his side. Andrews had advised moving slowly, and it had been seven months since Wynn's last visit.

"I'm here on behalf of the family," said Long, introducing herself to the doctor.

As Andrews scanned a recent MRI, Long tried to break the tension. "The good news is that you have a brain," she joked.

"Now I have to figure out how to use it," volleyed Wynn, who reported that the whistling in his ear was now rare. His face also had recovered.

"Something's there," Andrews noted. "It's little."

He flipped through results of a hearing test that showed some loss. Wynn looked concerned. "Is that significant?" Long asked. "It may not be," Andrews said, adding it could be age-related.

The doctor turned once more toward the two MRIs. Long noted that the spot appeared no brighter than it had earlier, a sign the tumor hadn't grown. In fact, Andrews said, the area looked slightly better.

It might only be inflammation from an infection, he said, not a tumor at all.

Andrews asked Wynn to return in six months. "I don't think this is acoustic neuroma," he said.

"That's great," Long said, beaming. Her counsel had spared Wynn a risky surgery—and, it appeared, he might not need any procedure at all.

Afterward, the patient was all smiles. "She's asking the right medical questions that I wouldn't know to ask," Wynn said. "It made everything so much easier. I don't think I would do anything but a cold without an advocate."

And with that, Wynn headed back to work.

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