

Original Story URL:

<http://www.jsonline.com/story/index.aspx?id=566890>

We all have an interest in expanding patient advocacy

Posted: Feb. 18, 2007

The Public's Health



Renie Schapiro

Terms such as "patient-centered" medicine and "consumer-driven health care" might make you think that the patient is in the driver's seat when it comes to securing quality medical care.

If only it were so.

Health care is getting more complicated, and navigating the health care system is getting more challenging for the average (and even the most sophisticated) consumer.

A patient diagnosed with a serious condition faces myriad decisions. How do I get prompt access to the best care? How do I understand and decide among the treatment options? What does the best research show? Should I join a clinical trial? Will my insurance cover expenses, and what if I don't have insurance? How will this affect my work and family?

All this at a time of high stress, when the simplest decision can be overwhelming.

And millions of people are trying to navigate the system for ailing parents who may live in other states.

Who couldn't use some help with the medical, emotional and financial challenges of illness?

A growing number of individuals and organizations are offering to provide it.

"The compounding of all these issues, together with people feeling that they have the right, and maybe

even the obligation, to take some control over these decisions has meant that (patient) advocacy in a lot of different areas has grown," says Marsha Hurst, director of the Health Advocacy Program at Sarah Lawrence College in New York.

Created in 1980, her program is the only one in the country that awards master's degrees in health advocacy. But more schools, including Stanford, the University of North Carolina and the University of Wisconsin-Madison are beginning to train students to be patient advocates.

The term "patient advocate" or "health advocate" includes individual help and work toward systemic and policy changes. It has many faces.

At one end is Pinnacle Care, a corporation offering concierge service at rates as high as \$50,000 a year (plus a onetime \$15,000 fee). Depending on the tier of service, clients get help ranging from organizing their medical records to accessing the best doctors around the world.

There also are corporations that contract with employers to provide health advocacy services to their employees. Some public programs serving low-income patients, local government offices and non-profit groups provide some assistance navigating the system of care and payment.

But Hurst says "access to advocacy for the average middle-class person is most difficult."

Health care professionals typically have limited time and little training in the broad range of issues patients face. Hospital patient relation offices have their own limitations, given their ties to an institution and especially in the face of budget cuts and concerns about risk management.

In Wisconsin, we have UW's Center for Patient Partnerships, an interdisciplinary program of the Schools of Law, Medicine and Public Health, and Nursing. It has been widely lauded as a leader in the field.

For no charge, a patient with cancer or another serious illness can get help from a law, social work or health professions student trained in advocacy.

Since 2001, the center has served about 900 patients. Director Meg Gaines created the center after her own battle with ovarian cancer.

She wants to help patients take control of their care. She and her colleagues also work for institutional changes, such as improved access to specialists or clinical trials.

Meanwhile, the center is preparing future professionals to be better advocates for patients.

The center relies on foundation support and private donations, taking no money from any entity that profits from health care.

Funding patient advocacy is one of the challenges of this field.

Another challenge is the issue of quality control and credentialing. Right now, says Gaines, "Anyone can put out a shingle and say 'I'm a patient advocate.' "

Patient advocacy is, she says, a nascent "profession." People in the field are beginning to come together to consider how best to develop the field.

All of us have an interest in that.

Renie Schapiro works at the University of Wisconsin School of Medicine and Public Health on the Innovations in Medical Education Team. Her column appears on the third Monday of each month.

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