



### **Sue Ann Says...When it Comes to Your Health Care, Put Fate Aside**

Some believe everything sails along with fate, while others feel destiny is not so simple. Meg Gaines is one woman who wants to steer her ship, “while I may not be able to control the outcome, I can certainly get my oar in the water and have whatever influence I can.” When Gaines, founder of the Center for Patient Partnerships, was diagnosed with ovarian cancer that had spread to her liver in 1994, it was a fight against the odds. “One doctor told me to go home and think about the quality rather than the quantity of my days. Had I heeded his advice, I would have died with no one knowing I needn’t have.” This was her first lesson in navigating her health care. “You are the captain of the ship, and the ship does not leave the dock without you. If you don’t feel comfortable with the journey as mapped out, you need more opinions, more advice, more information. At the end of the day, you are in charge of your health care decisions.”

Gaines’ message is important when you look at today’s health care system. It’s hard to imagine taking charge in a sea of confusing policies and intimidating procedures. Often the goal of providing excellent care is overshadowed by insurance coverage limitations. For those who do not work in health care, medical terminology is confusing and overwhelming. “Many patients fear they won’t understand an answer, so they quickly stop asking questions. They just need someone there to say ‘you can do it, let me help you get started’ ” Gaines explains.

That’s where the Center for Patient Partnerships can help. After Gaines’ experience with cancer, she and several colleagues established the Center for Patient Partnerships at the University of Wisconsin-Madison in 2001. The Center helps patients with life threatening and serious, chronic illnesses and their families unravel the

mysteries of the health care system. By teaming patients with future health care and other professionals, the Center helps patients understand diagnosis and treatment options, address insurance coverage and other financial impediments and strategize employment challenges. Supervised by professionals trained in law, medicine, nursing, engineering and psychology, graduate students from those disciplines and others including social work and pharmacy help patients from “Texas to Thailand and Portage to Portugal” free of charge.

The Center’s advocacy approach is characterized by two important principles: the commitment to raise future professionals’ awareness of the issues patients and their families face when dealing with illness and to create capacity in patients and future health care professionals to truly collaborate in health care decision making. “We teach students from a wide range of areas what it is like from the patient’s point of view *before* they step into their professional suits and get into ‘fix it’ mode. Future doctors, nurses, lawyers, pharmacists, etc. come to think of themselves as the patient’s team mates – as facilitators of a crucial process of learning about and choosing appropriate health care interventions.”

Likewise, the Center is committed to creating capacity in patients and their families to step up and participate fully in difficult health care decisions. “We don’t do for people what they can learn to do for themselves” Gaines says. “We help identify patients’ innate strengths – the skills that have served them well in their lives already – and build on these – complemented by effective support from family and friends. A strong team can make a real difference in health care outcomes.”

As ‘baby boomers’ age and the numbers seeking health care increases, effective self advocacy skills become increasingly vital. “While passive patients who just say ‘yes doctor’ may save professionals’ time in the short run, the best health care providers enjoy treating patients who are fully engaged in their care,” Gaines explains referencing a July Washington Post article by Dr. Marc Siegel. Dr. Siegel describes himself as a former “card-carrying member of the group of doctors who resent know-it-all patients.” He continues: “fortunately, my jaundiced view has given way to an appreciation for patients who inform themselves. It turns out that patients we acknowledge as stewards of their care tend to be more satisfied with their treatment. Several studies also seem to suggest that informed patients tend to have better outcomes.”

It seems patients who take the helm on their own health care journeys make positive results more possible. However, Gaines warns at some points patients don't feel they have the skills to take control. "It is crucial, then, to have assembled people – skilled professionals and family or friends whom we trust to take command when the best we can manage is to grab an oar or go below and sleep. Successful health care consumers also must know when to turn the helm over to a trusted team mate."

If you or someone you care about needs help, contact the Center for Patient Partnerships at (608) 265-6267 or email at [cpp@law.wisc.edu](mailto:cpp@law.wisc.edu).

So what's the message? It's time to put fate aside when it comes to healthcare. While outcomes cannot always be favorable, consumers and providers can maximize the possibilities by working effectively together. Meg Gaines exemplifies what it means to be a strong advocate for your health. "No one cares more passionately about your health than you."

- 1.) Siegel, Marc. *Who's in Charge? It's Your Care. Take Control of It, Recommends One Physician.* The Washington Post. 11 July 2006, pg. HE01

*The Wisconsin Women's Health Foundation (WWHF) is a statewide non-profit organization whose mission is to help Wisconsin women and their families reach their healthiest potential. WWHF presents women's health education and outreach programs, funds women's health research, provides scholarships for women in academic medicine, and publishes resource materials. Your donations help the Foundation reach women all over Wisconsin with the information, resources and tools they need to be healthy. To make a donation or to learn more about WWHF visit [www.wwhf.org](http://www.wwhf.org) or call 1-800-448-5148.*