

Cancer 'coaches' sway treatment choices

By MARILYNN MARCHIONE, AP Medical Writer Sat Feb 16, 12:16 PM ET

The advice made her head spin: Have the lump removed. No, let them take the whole breast. Chemo? Radiation? Everyone seemed to have an opinion.

"I just shut everyone down around me," said Bernie Brann, a newly diagnosed cancer patient from upstate New York. "You're just so overwhelmed with information."

Bad advice, or just too much of it, can compound the trauma and damage done by the disease itself, cancer patients often find. Friends and relatives are important for support, but when these untrained people act as cancer coaches, they can sway people to make poor decisions about their care.

This includes survivors, whose opinions are highly valued by patients suddenly facing the scary diagnosis. They may know a lot about cancer, but can do harm if they project their own experiences onto someone else, who may have a different form of the disease that needs different treatment.

Survivors also may be out of touch with changes in the field, where genetic discoveries are rapidly reshaping notions of who needs chemotherapy and what kind.

What's the solution?

Many advocacy groups and hospitals are using "professional" coaches — trained paid workers who can objectively help new patients navigate the maze of information and options.

The American Cancer Society started a "patient navigator program" a few years ago that now operates in 87 locations and is planning to expand. The National Breast Cancer Coalition also trains coaches, and big treatment hospitals like the University of Texas' M.D. Anderson Cancer Center are increasingly using them for breast, prostate, lung and other types of cancer.

Attendance set records in December at one of the top training programs, held during the San Antonio Breast Cancer Symposium. More than 240 breast cancer survivors spent late nights at the convention center, taking notes as scientists schooled them on the latest research.

Demand for this training is so great that the Alamo Breast Cancer Foundation gets grants from the Avon Foundation and nine drug companies to subsidize some attendees, but still can't meet the need. Dozens are turned down each year.

To find a coach or navigator, patients can ask their doctors, local cancer hospitals or groups like the cancer society for help. Brann, feeling a need for unbiased help, found a coach by calling the Cancer Resource Center of the Finger Lakes, where associate director Bob Riter provided it.

"People are usually too free about giving advice," said Riter (pronounced RITT-er), a survivor of male breast cancer and graduate of the San Antonio program. "We never tell people what to do. We provide information, and we help them think out loud."

A good cancer coach should offer these things, experts say:

_Support: an ear to listen, a shoulder to cry on, a hand to hold.

_Resources: reliable information or help getting it, and only if the patient wants it.

_Objectivity: a willingness to help patients discover what is best for them, rather than to validate the coach's own cancer battle and choices.

"There's a big difference in saying, 'This is what I did' and 'Here's what you should do,'" Riter said.

No hard numbers exist on how many cancer patients bring coaches or informal ones — a relative or friend — to doctor appointments where treatments are discussed.

"The person coming with you can either be an asset or a liability," said Meg Gaines, a lawyer and ovarian cancer survivor who runs the Center for Patient Partnerships, an advocacy resource at the University of Wisconsin-Madison.

It is good if the coach can ask questions, gather information and take notes for the shell-shocked patient to use later, she said. It is bad if the coach interferes with the patient's decisions.

Doctors often find themselves in the middle, fighting for the patient's trust. Some choices come down to personal values and risk tolerance, said Dr. C. Kent Osborne, a breast cancer specialist at Baylor College of Medicine in Houston.