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Medicine

A more personal show of support

* Not everyone is comfortable with group therapy. Some with cancer and other conditions say they get along just fine with help from family and friends.

By Marnell Jameson , Special to The Times

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When Julie Aigner-Clark was diagnosed with breast cancer last February, the first thing she did was learn as much as possible about her disease. She also checked out support groups.

Joining a support group, as her doctor and several organizations advised, is what people who are determined to defeat their illness do, she believed.

But the 38-year-old mother of two, who is also the founder of Baby Einstein Co., never got around to it. Although her tumor was small and contained, the cancer itself was an aggressive form. She had a double mastectomy 10 days after her diagnosis, followed by reconstruction five months later.

"I was busy enough trying to tend to my disease and my family. I didn't need one more 'have-to,' " says the Centennial, Colo., woman. "Plus, I was getting so much good information online, my husband was very supportive and, through friends, I was meeting other women in my shoes. I didn't see how a group would benefit me."

At times, however, she did worry. Well-publicized studies had found that support groups for women with breast cancer could prolong their lives.

But newer research could ease the minds of people like Aigner-Clark who have cancer or other conditions but who prefer to keep to their routine or to their own circle of friends and family. Support groups may improve the quality of life, a recent study found, but they don't prolong it.

"Many people think that not going to group will make their disease

worse," says Wallace Sampson, emeritus clinical professor of medicine at Stanford University and a retired oncologist. "That just isn't true. Psychosocial support may result in better adjustment and life quality, but it does not directly affect the evolution of human cancer or most other organic diseases."

In a report recently published in the Journal of Clinical Oncology, researchers studied 300 women with early-stage breast cancer who were undergoing chemotherapy. One group went to weekly group therapy sessions led by a professional. The other group did not. The difference in survival rates was not statistically significant: The group that went to therapy had an average survival time of 81.9 months. The control group lived an average of 85.5 months. The authors concluded that cognitive group therapy did not prolong survival in early-stage breast cancer patients.

"People shouldn't go to group sessions thinking they are going to prolong their life," said David Kissane, lead author of the study and chairman of the department of psychiatry and behavioral sciences at Memorial Sloan-Kettering Cancer Center in New York City.

The study is one of several that refute a widely publicized study, which appeared in the medical journal the Lancet in 1989, that said support groups did have a positive effect on longevity for women with breast cancer. That study spawned a generation of support groups for people suffering from all kinds of disease.

According to Sampson, whose patients were part of the 1989 study, "Later analysis showed no significant difference between the groups studied. The researchers didn't take into account other prognostic factors within the two groups that likely explained the survival difference."

Even David Spiegel, associate chairman of psychiatry at Stanford University School of Medicine who conducted the 1989 study, has backed away from the findings: "The studies have been mixed," he said. "The jury is still out [on support groups' role in longevity]. Certainly there's no harm in going, and groups do emotional good."

Though many people find that professionally led support groups help ease their depression and help them cope better with their disease, some can get along fine without them.

When Dave Escapite's doctor first suggested he go to a support group for people with Parkinson's disease, the 73-year-old retired printer went to a group near his home. After several meetings, he

stopped going.

"I already knew what they had to say about diet and exercise, and I get plenty of emotional support from my wife and friends. The group just wasn't for me," said the Fullerton man, who was diagnosed with Parkinson's nine years ago.

Kissane says such decisions are personal -- and can only be made by the patient. "If a person's life is going well, they are coping with their disease, living life authentically, feeling well supported and know themselves well enough to know the group experience is not one they would choose, so choose not to join, that's valid," says Kissane. "One never wants to induce guilt in these people."

However, he adds, if people are staying away out of fear or apprehension, they should talk to a professional about what the group experience is really like. If they're still unsure, they should go to a few meetings. If they still don't feel comfortable, or want to keep their disease private, they should consider other options for support, including individual or couple counseling, telephone counseling, and even online support groups.

Online support offers three advantages: more privacy -- you don't have to see people face to face; greater convenience -- you don't have to leave home; and a larger network -- you can interact with people whom you couldn't meet otherwise because of geographical distance.

People should also keep in mind that support groups help different people at different stages. "What may not be right for you now, could be later," says Annette Stanton, professor of psychology, clinical psychologist and researcher for UCLA's department of psychology, and a leader of many support groups.

But, she adds, "I would never hold out the hope of longer survival as a reason to join a support group. Anyone who implies that the mind can control cancer doesn't understand much about cancer."

Sampson wonders if groups are the best use of time for people living with chronic disease.

"These people have limited energy and time. If what matters to them is quality of life, do they really want to sit in a room and share their feelings with 11 strangers? Or would they rather spend time seeing a beautiful park or being with loved ones?"

Aigner-Clark's doctors urged her to have her daughters, ages 10 and 7, join a support group for kids whose mothers have cancer. "I wasn't about to go there. I knew my kids would be around other kids whose mothers were dying, and I wasn't going to die."

Support groups aren't for everyone," acknowledges Susan Daniels, who leads support groups for the American Parkinson Disease Assn. in Orange County.

"People can always find information and support from books, the Internet, nonprofit organizations devoted to their disease, medical professionals, friends and family. APDA's goal is not to make people join groups, but to ease the burden."

For Escapite, the decision comes down to this: "Unless the group is going to reveal the outcome of some new stem cell research that would improve my condition and be available tomorrow, I don't see why I'd go," he said.

PHOTO: INNER CIRCLE: Julie Aigner-Clark, with her husband, Bill, and their daughters, Aspen, 10, and Sierra, 7, says she was too busy trying to deal with her breast cancer diagnosis and her family to join a support group. " I didn't see how a group would benefit me."
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