

Support groups play crucial role in emotional recovery

Networks provide venue for sharing experiences and information on treatments

By DEBBIE WALTZER

Steven Stello's life changed forever on Oct. 5, 1998, when his doctor told him he had non-Hodgkin's lymphoma, a potentially life-threatening cancer. Five months later, Stello says, a support group at Gilda's Club Rochester helped him get his life back.

"I learned that night that people with cancer can tell jokes and go on vacations," says Stello, 49, a research technician for Carestream Health Inc. "The support group ... let me know that I wasn't alone."

Participating in a support group is a personal decision, says Ann Savastano, director of patient and family services for the American Cancer Society, Lakes Region.

Roughly 6,000 individuals within the region's seven-county area will be diagnosed with a form of cancer this year. Some individuals thrive on sharing their experiences and learning from others who have traveled similar paths, while others prefer to process the experience with their own support network of family and friends.

"I think that support groups are great for a certain segment of the cancer or caregiver population, while for other folks, it's just not the right fix for them," says Savastano, a 28-year cancer survivor. "The good news is that there are numerous cancer support groups in this region to help those who want to participate."

Savastano is an advocate of hybrid sup-

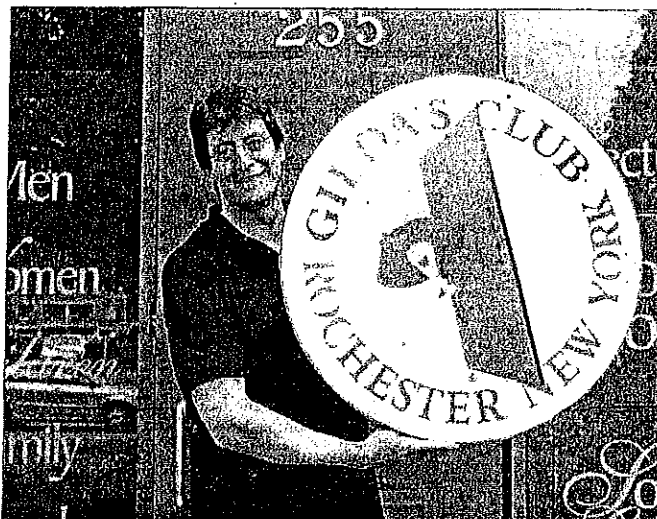


Photo by Kimberly McKinzie
"My support group at Gilda's Club taught me that I would go through a cycle of emotions during my cancer journey, and that was OK," says Steven Stello, a research technician with Carestream Health, who joined a support group after being diagnosed with non-Hodgkin's lymphoma some years ago.

port groups, which have an educational component as well as a format for participants to share with one another. For example, the American Cancer Society offers groups called "I Can Cope." Typically, an expert or two will attend such a group session and provide information about new forms of treatment. Participants are encouraged to ask questions and share their experiences with others.

Still, traditional support groups continue

to thrive for individuals with cancer and for those close to them who also are affected by the disease. In fact, Savastano notes, many individuals continue to participate in groups long after their disease has gone into remission.

"These folks want to keep helping others and give encouragement to people who are newly diagnosed with cancer," she says.

Dozens of cancer support groups convene on a regular basis throughout the

Rochester region. Some are hosted by non-profit organizations, while others are connected with medical treatment facilities.

For instance, patients and their families can tap into one of several support groups hosted by the social work team at James P. Wilmot Cancer Center at the University of Rochester Medical Center.

Examples include its gastrointestinal cancer support group, adult brain tumor network, metastatic breast cancer support group, and oral, head and neck cancer connection. In addition, Wilmot Cancer Center offers caregivers' support groups and is creating a young cancer survivors group, as well as a bladder cancer support group.

Support group participants can benefit greatly from their involvement, says Carmen Signorino, a senior oncology social worker at Wilmot Cancer Center.

"When people are diagnosed with something like cancer, they are often looking for some very practical information as well as emotional support from people who truly understand the situation," she says. "People feel less alone when they're able to connect in these situations."

Adds Signorino: "We find that participants often network on their own as a result of their involvement with the group. People who are newly diagnosed with cancer can learn from others who have been going through this for a while, which is truly beneficial."

All support groups at Wilmot are open to the community and often feature speakers who offer information about the disease, including side effects of treatment as well as quality-of-life issues.

Stello found his support at Gilda's Club
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SUPPORT GROUPS

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Rochester, a social and emotional cancer support community founded by comedian Gilda Radner after she was diagnosed with ovarian cancer.

Gilda's Club Rochester—one of 23 such facilities in the U.S.—operates under the slogan "Cancer support for the whole family, the whole time," says Julia Price, assistant director of public relations and marketing.

The local club, with numerous support groups as well as social activities and other resources, is free for all participants, who are called members. The organization, funded through grants, donations and fund-raising events, has an annual budget of \$750,000, a paid staff of six and a pool of 200 volunteers.

In 2008, Gilda's Club recorded more than 14,000 individual visits, up from 12,400 in 2007, Price notes. Facilities include a children's play area, a studio for arts and crafts, book clubs and areas for yoga and gentle exercise.

The organization offers numerous niche support groups each month, like its lymphoma/leukemia and prostate groups or

those that reach out to Spanish speakers, deaf women or women of color.

Meeting rooms for support groups at the club feature oversized, comfy chairs and couches, with blankets and boxes of tissues.

"Support groups for people with cancer, as well as their loved ones, are essential," Price says. "We have excellent medical treatment facilities in this community, but the sole focus of Gilda's Club is to address people's emotional needs.

"This is a positive and uplifting place," she continues. "Our goal is to help people live well with cancer."

Even though Stello has been done with cancer treatment for five years, he continues to stay involved at Gilda's Club. He and his wife, Lee, volunteer on Monday nights as facilitators for new member meetings.

It is his way of giving back, Stello says.

"My support group at Gilda's Club taught me that I would go through a cycle of emotions during my cancer journey, and that was OK," he says. "Cancer is limited—it can't shatter hope, destroy faith or kill friendships. And support groups are an important part of emotional recovery."

Debbie Waltzer is a Rochester-area freelance writer.

BETTER OUTCOMES

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Medical Center at Fort Sam Houston in San Antonio, Texas, a fellow medical resident broke his arm and missed his cardiology rotation. The resident offered to trade his oncology rotation for Cadiz's cardiology rotation, and she agreed.

Cadiz, who initially interviewed for a temporary post at Pluta but was offered a permanent position during the on-site interview, says cancer care options in Rochester and Upstate New York are varied and excellent.

"Every physician, I think, has their own style, and every patient is an individual," says Cadiz, who spends what little free time she has with relatives in Syracuse.

Monson's first taste of Rochester came as a visiting professor at URM. He says the community's welcoming people and proximity to water reminded him of his prior post at the University of Hull in England, where he was a surgery professor, head of the academic surgical unit and deputy head of the medical school. He joined URM as chief of the division of colorectal surgery and vice chair of the department of

surgery in 2008.

Since his time as a student in the 1970s and 1980s at the University of Dublin's Trinity College, Monson says, treatment for leukemia, lymphoma and testicular cancer and medical imaging have vastly improved.

"That's a phenomenal change in a trivial amount of time. That's only 30 years," says Monson, who specializes in minimally invasive and laparoscopic techniques for colorectal surgeries, including cancers.

Still, the author of 220 peer-reviewed papers notes that "not everything is rosy in the garden."

"Sometimes patients still present with advanced disease," Monson says. "They didn't go see their doctor, or they get a complication after surgery or, despite everything, you haven't cured them."

Like most doctors waging war against cancer, Monson, a vintage race-car driver and collector in his spare time, loves his work. The challenge of learning and developing new surgical techniques keeps him pressing forward.

"It's never boring," he says.

Sheila Livadas is a Rochester-area freelance writer.

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Statistically, she says, women in the middle of the United States often are likely to choose mastectomy over chemotherapy because they do not live close to a treatment center.

MammoSite saved Michele Bessette's life, she says. A patient from the Lipson Cancer Center, Bessette credits technology for detecting her breast cancer and then killing the cancer cells.

"I went in on a Tuesday, then Saturday they had me for an ultrasound and biopsy; by next Tuesday my doctor called me with results," she says. "Technology told me what my treatment options could be."

The 48-year-old mother of three has a full-time career and is in her second year as a cancer survivor.

"I'm very old-fashioned—let's do it the way it's always worked," Bessette says. "But MammoSite sounded great.

"I could get back to my life in five days, not six weeks. I wanted to have those treatments behind me faster."

Bessette acknowledges that the treatments were exhausting.

"Radiation takes its toll," she says.

But other than fatigue and the emotional toll, Bessette says, the 30-minute MammoSite treatments were not as difficult as she might have expected cancer treatments to be.

Lori Gable is a Rochester-area freelance writer.

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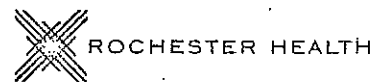
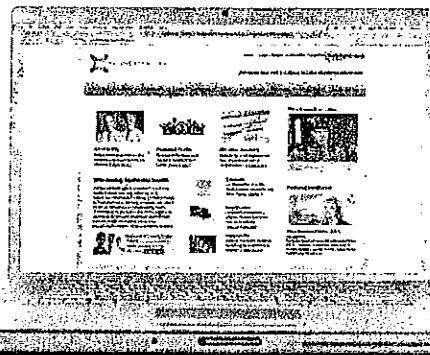
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