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On Their Own

BY MARC SILVER

Solitary cancer patients call on inner strength and a raft of resources.

In the midst of chemotherapy treatments for non-Hodgkin lymphoma, Jim Burnham would sometimes crave a cup of tea. A retired salesman who's now 66, Burnham is single and lives alone in Seattle. So he had only one option: "You get up and you make your tea, or you don't have the tea."

Sure, he has friends. Some act as if his lymphoma were contagious. Besides, he says, "cancer is such an isolating circumstance—people can walk you up to the door, but you're the one who's going in."

There's an army of solo cancer fighters like Burnham. They are alone for a variety of reasons. Some prefer the solitary life. Or they may be alone because of circumstance: older people who've lost a spouse (and many friends) as time has passed, new immigrants, young people who've moved to a new city, folks in midlife who've seen a marriage crumble. If they have family members who live far away, the rising cost of gas and airplane tickets may hamper their ability to visit.

Call them "independent" or "isolated" cancer patients—both adjectives are appropriate. They're proud of their ability to handle things on their own, although they may not have come up against anything quite like cancer before. And they may feel a suffocating sense of loneliness as weeks and months of treatment drag by.

The medical community tries to identify and reach out to single patients from the get-go, and for good reason. Studies show that people who live alone have a harder time coping with a cancer diagnosis. Social support, such as having a loving, caring spouse who helps provide food and transportation, confers a degree of well-being and has a protective effect, says psychologist Anne Coscarelli, PhD, director of the Simms/Mann-UCLA Center for Integrative Oncology at the university's Jonsson Comprehensive Cancer Center.

"You can have the best treatment plan, consisting of the most sophisticated form of chemotherapy, radiation therapy, and surgery," notes Judith Shepherd, MSW,

DSW, of psychosocial services at Alta Bates Summit Comprehensive Cancer Center. “But without transportation, you can’t get those treatments. It’s that serious.”



Jim Burnham managed the day-to-day of treatment alone. Photo by Jennifer O'Donnell/Tumble Bumble Photography

Finding Help

Solo fliers do find ways to cope and thrive, calling on their inner strength as well as local and national resources.

In the days after diagnosis, the independent cancer patient may need someone to cut through red tape and sort through information—a friend, volunteer, or professional. Social worker Kathy Gurland, MSW, LCSW, who just started a New York business as a navigation consultant for cancer patients, got a call from a single client in a panic. An entrepreneur in her early 40s, the caller wanted a second visit with her surgeon to discuss her upcoming surgery for ovarian cancer. The office scheduler said sure, how about the day before the operation? Gurland encouraged her client to ask the office social worker to intercede. The client quickly got a slot. Gurland came along, taking notes and prompting the woman to ask her questions—taking the role a spouse or parent might play.

Decisions are difficult for any cancer patient, perhaps more so for the independent operator. “A single person has to trust themselves a whole lot more,” says Cathleen Carr, 52, of Tacoma, Washington. An experienced researcher from her work as a consultant, Carr dived into the web to learn more about her breast cancer, which hit in 1995 and returned in 2004.

Carr felt she waited too long before deciding to have a mastectomy after the recurrence. “Weighing information can be a way to stall. You have to have a sense of intuition.” Setting a deadline, with the input of doctors, is a helpful strategy.

When it comes to practical matters, single cancer patients may underestimate what they need. “They have no idea how cancer is going to, excuse the expression, kick their butt,” says Shepherd. “The exhaustion, the low blood cell counts, all of these things are so debilitating.” It’s incumbent on the medical team “to keep checking and keep offering,” she says. Over time, there could be a change of heart

in a patient who initially fears that accepting assistance would mean a loss of independence.

Others want to ask for help but may be wary of rejection. A single mom when she was diagnosed with leiomyosarcoma in 2002, Sharon Anderson of San Francisco remembers how hard it was for her to reach out.

““ Cancer is such an isolating circumstance—people can walk you up to the door, but you’re the one who’s going in. ””

—Jim Burnham

“I made the assumption friends were busy, had their own kids,” says Anderson, now 50. “I didn’t feel close enough in those relationships where I could ask for help. That was a wake-up call that I needed those kinds of relationships. I needed to give that way, and to be able to receive that way.”

To a person reluctant to seek help, Coscarelli advises: “The first step is to say, ‘I’m worthy of help. I deserve this help.’ ” Besides, what’s the worst that can happen? Someone says no. Then you go to the next person on the list.

Reaching out to strangers can yield remarkable results. A woman once called The Group Room, a radio program about cancer hosted by Selma Schimmel, a breast and ovarian cancer survivor who founded the nonprofit Vital Options. The caller was terrified about an upcoming surgery for vaginal cancer. She didn’t know how she’d find the strength to walk into Memorial Sloan-Kettering Cancer Center. A listener called and said, “I’m a volunteer at Memorial. I will meet her in the lobby. She does not have to go alone.”

The web can also fill a void. Greta Greer, director of survivor programs for the American Cancer Society, recalls a posting from a woman at the nonprofit’s Cancer Survivors Network. No one cares about me, the woman confessed. She was going to stop her treatment. By the next day, 25 e-respondents had urged her to keep up her chemotherapy regimen. She did, and later wrote, “These people saved my life.”

Seeking Embrace

A support group can create a network of newfound friends. But groups are not for everyone. The solitary cancer patient may not want to open up. A group member is not obligated to talk, experts point out. Merely listening to others talk about their cancer experience can be instructive and inspiring.

But not always. “Some people say, ‘I can’t stand to hear other people’s stories,’ ” says Jimmie Holland, MD, a psychiatrist at Sloan-Kettering. “If it helps, great. If it doesn’t, don’t go again.” She suggests sampling the range of therapeutic experiences aimed at cancer patients such as counseling, meditation, art, music, and dance therapy.

A hug can also be helpful. “I did probably gather and give more hugs during that time than any other time in my life,” says breast cancer survivor Margaret Jeddry, 53, of Nahant, Massachusetts. “It is physically and emotionally so isolating, so if somebody offers you a hug and you’re not a huggie person, you’re much more apt to take it.”

Nurse and breast cancer survivor Lillie Shockney, RN, agrees. A patient who is alone “wants very much to hug somebody before going into the operating room,” she says, based on her experience as administrative director of the Johns Hopkins Breast Center. “It can be the nurse who put the I.V. in that they just met. They want to feel a connection to somebody. To me, that also means they want to have someone thinking about them while they’re in there.”

When there’s no one else around, a pet can offer solace. “My cat drove me to distraction during my treatment, demanding attention,” says Bill Hall of Seattle, who underwent 12 weeks of chemotherapy for lymphoma. “But having to care for something other than yourself was, in the long run, more beneficial than words can express. Having Chloe crawl up on my chest and take a nap is heaven.”

Profiles in Courage

As for studies that report how hard cancer is for independent souls, well, it is hard. But that doesn’t mean it’s impossible. “I’m always impressed with how courageous people are, how amazingly well they handle an awful situation,” says Holland.

Daniel Jordan, 31, a recovering alcoholic who lives in a homeless shelter in Seattle, is battling stage 3 melanoma. He takes the bus to the hospital for his treatment and is grateful to get a free ride because of his cancer.

“I try to keep a positive attitude,” Jordan says. He’s studying to become a welder and is hopeful about the future. “I want to try and buy me a big sailboat. I’m not gonna let this stop me. It’s driving me to stay sober and achieve things.”

Jim Burnham isn’t so sure it’s a positive attitude that’s seen him through his ordeal—the chemotherapy in 2005 caused his weight to drop from 180 to 130 on his 5-foot-10½-inch frame, and he’s still recovering from the stem cell transplant from last December.

“The truth of the matter is you’ve just got to be self-reliant,” he says. A lymphoma support group has been “a surrogate family” when it comes to talking about his cancer. But in his daily routine, he gets by on his own. He drives himself to doctor’s appointments, makes his own meals, and watches TV—“but only things that make me laugh. I have enough anger and sadness in my system.” With laughter and self-reliance, this solitary warrior aims to conquer his cancer.