Being Your Own Caregiver During Cancer

Friends, siblings, support groups and social media can all make a huge difference for patients who are “cancering” on their own.

November 28, 2023 By Fred Hutch News Service and Diane Mapes

When I was diagnosed with stage 3 lobular breast cancer in early 2011, I didn’t have a caregiver. TBH (to be honest), I didn’t even know what a caregiver was; I kept getting the term mixed up with care provider.

“Who’s my caregiver? I am!” I told anyone who asked. And it was true, in a manner of speaking. I regularly bussed or taxied myself to the scans and oncology visits and infusions and radiation blasts. I shopped for groceries and lugged them home. I figured out my meds; kept my countless appointments straight. And I worked, albeit at home.

But I was not doing cancer alone.

I didn’t have a designated person, a husband or partner or parent by my side every step of the way. But I had people — an ever-shifting band of sisters, friends, neighbors, colleagues, acquaintances and even kind strangers, thanks to the incredible cancer community on social media. My people made meals, did chores, took me for walks and hauled me to and from the hospital as needed. They opened my pill bottles (chemo can really weaken your hands), helped me out financially. They fought with me over the laundry basket.

They say it takes a village to raise a child; it’s not much different for those doing cancer alone.

A caregiver who can help you cope with the day-to-day Sturm und Drang of cancer and treatment is a wonderful thing. For those getting a blood or marrow transplant, it’s not just a nicety, a dedicated caregiver is a requirement. But it’s not just having somebody to help with chores and car service. You also need someone to help you emotionally process what you’re going through: cancer and treatment mess with your mind as much as your body. Caregivers help with that, too. Studies show that the health and well-being of a caregiver can impact a cancer patient’s outcome.

Caregivers absolutely matter, but they are not a given. Not everyone’s married or partnered or has a grown child who can move home for a while. And people who are married (all right, women who are married) often find themselves left in the dust after diagnosis, anyway, at least according to a

2009 Fred Hutchinson Cancer Center study on partner abandonment.

Think going through cancer treatment on your own is impossible? Shudder at the thought of asking friends and family or even strangers for help? I talked with a handful of patients who powered through cancer without a designated caregiver to get their best advice on going solo during treatment. Read on for their insights.

Gathering Your People

When Helen Self, 58, a former magazine editor and mother of three from Bath, UK, was diagnosed with an early-stage breast cancer at 53, she was in the midst of an acrimonious divorce and had a teenage son at home. The rest of her family was unavailable: her older boys lived out of town, her parents were dead and her only sibling had a "hospital phobia and vanished."

"The saving grace was my network of friends, and my 16-year-old son, who was a calm presence at home and did what he could alongside his schoolwork," she said. "My friends and one neighbor in particular rallied 'round and were fantastic."

But it was not easy. Self hated asking for help when the treatment side effects left her too weak to take care of her son or the house. She didn't want to be a burden.

Andrea Suzuki, one of Fred Hutch's clinical patient navigators, said that's a common concern.

"Losing autonomy is a huge fear for cancer patients without caregivers," she said. "They don't want to be a 'burden.' I hear that a lot from our patients. Trust is also a big issue. Some patients may not feel comfortable using someone from an agency to care for them at their most vulnerable."

Others feel overwhelmed by the unknown: not knowing how chemo will impact their day-to-day lives and whether they'll be able to work, work-out, drive, keep up the house.

Suzuki said she often brainstorms with patients who don't have caregivers, putting together a Plan A and a Plan B, just in case they might need help.

"I'll have them tell me about who's around them, their support system," she said. "Sometimes patients do have one but are embarrassed to ask for help. Pride can come into it."

Reaching Out for Help

It did for Self, who said she wove together a support network of around 10 friends rather than relying on one or two people which seemed like "too much pressure."

But when Self's first cancer surgery left her too exhausted to decorate the family Christmas tree,

she took to social media and learned asking for help could be a blessing.

“I felt so guilty for letting my son down, I finally swallowed my pride and posted on Facebook for help,” she said. “A woman I’d known 13 years previously immediately replied and came over with her daughters. They even brought a cold supper. We put on holiday music and they all decorated the tree. It was the kindest thing.”

Self and her youngest son have remained friends with the family. Ditto for the nonprofit volunteer who came by once a week to help Self with housework and keep her company.

“I really lucked out there, too,” she said of the volunteer. “She’s like my daughter now.”

Sure, there were times when the side effects were so debilitating that she had to give the bank card to her son so he could go buy groceries but she said she was able to power through by tapping available resources — local cancer nonprofits, friends near and far — whenever possible.

“Four years later I’m still in the clear,” Self said. “I now have a rewarding new career teaching English to refugees and asylum seekers and I’ve gained a wonderful kind-of-daughter and a new very close friend.”

Caregiver Options

Many patients (cancer and otherwise) use free websites like Caring Bridge to update friends and family on their health status and organize “meal trains” (where friends or neighbors prepare and drop off meals), grocery runs and chores.

No tech skills? No problem.

“If someone isn’t technically savvy, I’ll sit down and show it to them and help them set up an account for themselves,” Suzuki said.

But not everybody has a large circle of friends ready and willing to make meals, track appointments and argue with insurance providers on a patient’s behalf. If that’s the case, there are still options.

“You’d be surprised how many people are eager to help and will help patients,” Suzuki said. “But when there’s not anyone and if the patient has Medicaid, the state of Washington actually has people who can act as caregivers.”

In addition, friends, siblings or extended family can be trained to be informal caregivers — and be paid for their care. Suzuki said you have to meet certain requirements, but the Washington state program, known as COPES, works for some.

“You don’t have to have a medical or health care background,” she said. “You’re not changing IVs or giving injections or anything like that. It’s more like taking care of chores around the house and

reminding the patient to take their meds."

If patients don't qualify for this program, finding help may be more complicated, especially if finances are tight.

"That's when we have to have a hard conversation," Suzuki said. "I'll ask if they can afford to pay for a caregiver out of pocket."

Cancer.net, run by the American Society of Clinical Oncology, or ASCO, recommends patients in search of caregivers ask their care team for a referral to a home health care agency or contact Medicare's home health agency finder (you don't have to be on Medicare). Additional resources are available on the Family Caregiver Alliance website.

Even if you think you can do it alone, Suzuki said it's smart to line someone up just in case you become overwhelmed.

"I've heard from patients who thought they'd be able to cook for themselves, but then couldn't," she said. "The energy level they thought they'd have was nonexistent. They didn't understand how much a caregiver was needed."

Surfing for Support

Patients also reach out for help on social media sites like Twitter/X, Facebook or TikTok, asking for financial or other assistance. Lauren Malone, a cancer patient from Boston, posts on Twitter/X whenever she needs rides to chemo infusions.

"My appointments next week start at 9:00 in the morning Monday which means I'm going to have to get transportation on Saturday and it's going to cost quite a bit," reads one. "Please help if you can with the Go Fund Me. I really wish this humiliation would end and I would get better so I can go back to work. I promise you I'm trying."

Others find helpers through Imerman Angels, a nonprofit founded by a cancer patient that matches patients and caregivers in need of cancer support with people who've been there. And it's all for free. Imerman Angels also offers a downloadable cancer packet with dozens of resources and available en español.

The countless cancer communities on social media are a frequent source of support, especially for those dealing with side effects, "scanxiety," odd symptoms and/or fear of recurrence.

"Cancer patients are the only people who understand cancer treatment," said Mike Linn, aka @TheCancerSutra, a 35-year-old entrepreneur from San Luis Obispo, California, who was diagnosed with stage 3C melanoma five years ago, then had a metastatic recurrence a few years later. "It's hard for people who haven't gone through cancer to fully empathize."

Tips for Those Caring for Themselves During Cancer

- Identify helpers. Neighbors, colleagues, church members, pet sitters, friends, other patients — map out your entire network and see who can help. Share your “care map” with others so they can coordinate.

- Find your cancer family. Connect with other cancer patients, IRL or online. Nobody “gets it” like other patients; you can voice the things that would freak out family or friends.

- Figure out your meds. Have your medication schedule clearly written down and medicine bottle caps open.

- Ask for help when you need it, even though it may be hard. Or consider having a good friend ask others on your behalf.

- Record clinic visits with your phone if you can’t find someone to go with you and listen later with a friend/family member to clear up questions, confirm next steps.

- Or phone a friend/family member and have them listen in and participate in your doctor’s appointment with you.

- Plan ahead as much as you can. Prep and freeze meals for the future when you have energy. Set up temporary sleeping quarters on a main floor before it’s absolutely necessary. Keep an ongoing list of chores that you can give to your helpers.

- Estate planning. If it gives you comfort, make your wishes known via advance directives, wills, death with dignity arrangements.

- Remember cancer and caregiving are hard. Be kind to yourself always, especially if/when you don't have the energy for events, parties, appointments.

- Don't forget to find joy in life. Spend time in nature, listen to music, read, laugh with friends and family. Hang on to your life outside of cancer.

- Be prepared to be ghosted. Cancer is scary so you may have friends disappear after a diagnosis. On the other hand, many others will step up, unexpectedly.

- Explore all resources that can offer support including drug companies, cancer treatment centers, nonprofits, national cancer organizations, etc.

An online lurker during his first run-in with melanoma, Linn said he's since leaned into social media for much-needed emotional support. He especially recommends the cancer community @ThanksCancer on Twitter/X.

"I found Reddit and YouTube and Twitter to all be really helpful," he said. "You don't get any fluffiness from cancer patients. You get the best jokes, you get empathy and you can always find help."

Extremely fit (he ran a marathon days before his initial diagnosis), Linn did most of his own caregiving during his first go-round with cancer; his then-girlfriend helped out, too.

Their blossoming relationship was no match for melanoma, though.

"We were in the honeymoon phase of the relationship and suddenly I had serious cancer," he said.

They broke up after he finished his treatment in 2019. Then the pandemic hit. Three years later, his cancer progressed and he began immunotherapy infusions again. Then came complications.

"I hit every autoimmune side effect," he said. "Gastritis, hepatitis, colitis — all the itises; my thyroid died. I lost 35 pounds in a matter of weeks and had to pause treatment."

Luckily, he had "an incredible friend group" who brought him food and took care of chores around the house while he recovered.

Financially independent since he was 15, Linn said he has never been keen on asking others for help. But when you're facing a difficult diagnosis, he said, you don't have a choice.

“Having to rely on other people for help has been humbling,” he said. “But now I’m used to it. I can’t let my pride get in the way of things at this point. You have to face reality.”

Doing Double Duty

Linda Mahler, a 71-year-old retired university administrator from rural New Jersey, referred to herself and her husband as “kind of a heavy couple,” since he has Alzheimer’s and she has metastatic breast cancer.

“We don’t get invited to a lot of cocktail parties,” she quipped.

Her wide circle of friends and droll sense of humor have helped her navigate the double whammy of cancer and caregiving for herself and her husband. Social media has provided respite, as well.

As has her Mini Cooper convertible, which she bought for her 70th birthday.

“I’ll get into the car, put the top down and run an errand — that’s my self-care,” she said, adding that she also does jigsaw puzzles, listens to music, putters around in her vegetable garden and enjoys the occasional glass of wine.

Mahler admits the dual caregiving can be exhausting. It’s especially hard, she said, to leave her husband in the care of someone else whenever she goes in for her regular infusions.

“He doesn’t remember where I’ve been when I come home,” she said. “There’s no ‘Hi honey, how did you do? What did the scans say?’”

Despite the challenges, she keeps positive; she also tries to keep it all in perspective, knowing things could always be worse.

“Not to sound hokey, but I am grateful every day to be alive,” she said. “And I’m grateful every day that my husband is alive. He’s a really good man and I really believe we’re a gift to each other. Sometimes it’s hard, but we all just have to do the best we can do and not beat ourselves up if it’s not enough. Just do your best that day.”

Cancer & Caregiving Series
November is National Family Caregivers Month, which expands the spotlight to encompass the army of caregivers who do everything from taking notes during medical visits and keeping loved ones company during long hours of chemotherapy to caring for them at home as they cope with side effects from grueling treatments. The series of articles from the Fred Hutch News Service also includes:

- Self-care guidance for caregivers from seasoned caregivers.

- Tips on staying organized from two women who are caring for spouses going through blood cancer treatment.

- Families facing the challenges of cancer caregiving as the population ages.

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