

Who Takes Care of the Caregiver?

Self-care guidance for caregivers during National Family Caregivers Month

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Patient care is a team effort — with caregivers playing an important role. On a regular basis, dedicated caregivers juggle a wide range of tasks including scheduling appointments, managing medications, monitoring for side effects, tackling household chores and providing emotional support.

But who takes care of the caregivers? It's important to acknowledge — especially during National Family Caregivers Month, marked each November — that caregivers need care and support as well.

“So often the focus is on the patient and not as much on the caregiver, but the way I think of it, the patient and the caregiver are on a parallel journey,” said Amanda Hansen, a Spiritual Health clinician at Fred Hutchinson Cancer Center. “They’re both in the midst of the experience together, and folks don’t always recognize that.”

Self-care in the midst of caregiving is vital, but caregivers don’t always feel like they can take the time and space they need to focus on themselves. Yet when they do, both the patient and caregiver are better equipped to continue with their treatment.

“One of the major issues that comes up for a lot of my patients is the fear of being a burden,” said Rae Wiseman, another Spiritual Health clinician at Fred Hutch. “When caregivers take care of themselves, this patient fear can be somewhat alleviated. When patients can see that their caregiver is healthy and thriving, patients feel safe.”

As caregivers are honored and recognized today and every day, here are five ways that caregivers can focus on taking good care of themselves.

1. Check in on your physical needs

Caregiving is a huge responsibility, and one that can only be done well when your physical health is taken care of. Do a daily check-in with yourself: Am I drinking enough water? Have I had something to eat? Am I getting some sleep?

Simply put, “Some of that compassion that you’re pouring, pouring, pouring into that other person should also be directed at yourself,” Hansen said.

2. Acknowledge the validity of your feelings

“It’s really important to validate that caregivers are going through the same emotional ups and downs as the patient. They’re waiting on the same test results and experiencing a lot of the same exhaustion, fear and anticipatory grief,” Hansen said. Yet caregivers often don’t want the patient to know that they’re struggling.

“I didn’t want her to know I needed support,” said Thomas Lee, who cared for his late wife Jean as she lived with pancreatic cancer for over four years. “My greatest difficulty was keeping a straight face in front of her. Over 51 years of marriage, she always saw through me ... But very often I would tell my wife I was going to pick something up, and I’d just go down to the car and cry,” he said.

It’s important for caregivers to understand that their feelings and experiences are valid, even though they’re not the one physically going through treatment. More than that, it’s vital to acknowledge that a wide range of emotions are normal: exhaustion, fear, guilt, grief, helplessness and even resentment. Once you’ve named these feelings, you are better able to get the help you need to work through them.

3. Find simple joys

It’s common to get advice like “You should start meditating” or “Yoga might help you relax,” but if those activities weren’t part of your lifestyle before you started caring for your loved one, it’s probably not the right time to pick up a new hobby.

Instead, try to find small moments to reconnect with the activities that have brought you joy in the past. That might be reading, exercising, taking a long bath or baking. And with everything on your plate, it’s best to start small. While you may have previously enjoyed long weekend hikes in the woods, if that’s not realistic due to your caretaking schedule, even a walk through a neighborhood park in the fresh air may do some good. Take opportunities for “bite-sized” pieces of the activities that make you happy.

4. Take a break

When caregivers are responsible for medical care, such as administering medication and monitoring for side effects, it can be difficult to feel comfortable taking time away. But it’s also important to give yourself time and space to decompress and process.

“When we disconnect from our sources of joy and peace, the despair can set in,” Wiseman said. “Taking a break can remind you that there are other things than caregiving.”

Consider asking a friend or family member to come spend some time with your loved one while you take a shower, enjoy a quick nap, run some errands or reconnect with a friend. If paying a part-time or occasional caregiver is an option in your situation, it can provide a sense of routine and help you feel like you aren’t solely responsible.

Taking a break can also mean freeing up your schedule enough to spend some quality time with your loved one without worrying about household tasks. If you’re able to hand off some household chores to a friend, family member or outside service provider, it can allow some time to check in with each other without all the hustle and bustle of everyday life.

5. Ask for help

“It takes a lot of courage to ask for help, but it’s an important way to be less alone in the caregiving role,” Hansen said.

Even though many patients and caregivers have friends and family members who are willing — and probably have already offered — to lend a hand, don’t be afraid to accept their help. Consider the types of tasks a friend could take off your to-do list, whether it’s dropping off groceries, mowing the lawn or taking your dog for a walk.

“We had a lot of support from my son and daughter-in-law,” said Lee, who suddenly found himself in charge of cooking. “I was never allowed in the kitchen until my wife got sick! I would cook four days a week, then over the weekend my son would cook, so we’d go over to his house to eat together.”

Find support

When a loved one is receiving treatment at Fred Hutch, there are a wide range of resources available to caregivers. The [Spiritual Health](#) team provides guidance and support to caregivers of all faiths and spiritualities, as well as those who identify as nonreligious or nonspiritual. Caregivers are always welcome to visit the Fred Hutch Sanctuary in the South Lake Union clinic. [Social workers](#) can also help connect caregivers with educational resources, counseling and caregiver support groups.

No matter how self-care as a caregiver is approached, it’s important to acknowledge that caregiving is both challenging and rewarding.

As Lee said of his time as a caregiver for his wife, “I just took it one day at a time. It is difficult being a caregiver, but I don’t regret a single day of it. I was glad to be able to do it for her.”

SIDEBAR:

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 Fred Hutch News Service also includes:

- Advice for cancer patients on [being your own best support](#) and where to find community from other patients.
- 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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