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fact sheet

CAREGIVING FOR A LOVED ONE WITH A LONG-TERM ILLNESS

When you are caring for a loved one with a long-term illness, caregiving becomes a marathon rather than a sprint. A caregiver's involvement and role may change depending on their loved ones' health during and after treatment.

LONG-TERM CAREGIVING

The demands on a long-term caregiver can be considerable. In order to provide the best care, it is vital to also take care of yourself.

As a caregiver, it is important to know and accept your own limits. Stress develops whenever you start to feel that your responsibilities are greater than the time, energy or other resources that you have to meet them. Stress is common among caregivers of people coping with cancer who face so many competing demands. This can be especially challenging when your role as a caregiver may change over time, sometimes unexpectedly, depending on your loved ones' health. Finding ways to manage stress can help you feel better. protect your health and make you better equipped to care for your loved one.

Acknowledge your emotions. A chronic illness might make it necessary for you to adjust the plans you had for yourself, and this can affect you emotionally. Set aside a few minutes to reflect on your thoughts and feelings about the pressures and expectations you feel, and what it is that you would really like the day or month to be like for you. Writing down feelings can create a concrete record of your experiences.

Reflect on strengths you and your loved one have developed. Many families who face the challenges of cancer discover courage they didn't know they had. For example, you may recall how brave your loved one was while receiving chemotherapy or how successful you were in advocating for their needs.



Acknowledge these strengths and build on them whether your loved one is going through treatment or has a temporary break from treatment.

Adjust expectations, especially during holidays. A long-term illness may mean your loved one is in remission one year but undergoing treatment the next year. Consider if an upcoming event may place too much of a burden on you or your loved one. Think about how you've helped each other feel better during a difficult time in the past and how you can adjust going forward. Consider alternatives to the usual celebrations and the creation of new ones.

Find someone to open up to. Don't keep your emotions bottled up. Sharing your feelings with someone you trust—a partner, family member, friend, spiritual leader or social worker— can make your concerns seem more manageable. Caregiver support groups are also available. These can give you an opportunity to meet and learn from others in similar situations. CancerCare's professional oncology social workers provide free case management, counseling and support groups, including online and telephone support groups for caregivers, to you and your loved one to help you cope with your role as a caregiver.

Recognize that you are doing your best. There is no "right" way to be a caregiver. It's important to give yourself permission to acknowledge your efforts as a caregiver and to be patient with yourself as you navigate this role.

CancerCare® Can Help

Founded in 1944, Cancer Care is the leading national organization providing free support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include case management, counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All Cancer Care services are provided by master's-prepared oncology social workers and world-leading cancer experts.

To learn more, visit www.cancercare.org or call 800-813-HOPE (4673).

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HOW DO I CARE FOR MYSELF DURING THIS DIFFICULT TIME?

When unmanaged, long-term stress may increase your chances of developing chronic health problems, such as heart disease or high blood pressure. You need to make sure that you are caring for yourself so that you have the strength and energy to give your loved one the best care possible.

- Maintain contact with friends and family. Social isolation can increase emotional distress.
- Watch for signs of emotional distress: constant sadness, fear, panic or anger. If any of these symptoms make it difficult for you to accomplish your daily tasks, speak to a doctor, nurse or social worker.
- Listen to friends or family if they notice changes in your mood. Sometimes they see changes that you might not recognize yourself.
- If possible, try to give yourself a half-hour to an hour each day outside the house.
- Remember to eat three meals every day. Even if the meals are small, they will give you energy to take care of your loved one.
- · Drink water regularly.
- · Take time to exercise.
- Try to get uninterrupted sleep (6–8 hours). This might require that you get some assistance in caring for your loved one at home.
- Allow yourself time each day to have quiet restorative time.
- Keep up with your own doctor's appointments and medications.
- Reach out for support.
- If you think you may be experiencing burnout, see our fact sheet "Advice for Caregivers: Handling Burnout" for more coping strategies.

Edited by Mary Hanley, LCSW This fact sheet is supported by Takeda Oncology.

