

Caregiving for a Parent

CANCER CAREGIVERS

Helping the Helper

Frankly Speaking About Cancer



Family members who take on a caregiving role feel cancer's deep emotional impact. You may feel a roller coaster of emotions—from joy to sadness or from closeness to loneliness. These emotions may even occur all in one day. You may have to navigate changes to your relationship and consider decisions you never thought of before.

This resource is for adults serving as a caregiver for a parent diagnosed with cancer. It will discuss navigating this unique role and shared decision-making. It will also talk about ways to reduce stress and the emotional impact of cancer. At the end of this piece, you will find helpful resources for support.

WHO ARE CAREGIVERS?

The term caregiver describes anyone who provides or arranges help for a person with a health concern. This type of help includes physical, emotional, spiritual, financial, or logistical support. A cancer caregiver is anyone who provides support and informal care to someone diagnosed with cancer. In this resource, the term “loved one” is used to describe the parent diagnosed with cancer.

In the United States, nearly 53 million adults identify as a caregiver. That is more than 1 in 5 people. Middle-aged adults often serve as the primary caregiver for a parent as they get older. Adults caring for one or both of their parents make up about 44 percent of the caregiving population.



NAVIGATING THE CAREGIVER ROLE

Everyone’s cancer experience is unique. The decisions and support needed for one person may differ from someone else. Some caregivers find that they often help with daily activities. This can include bathing or assisting their loved one with their medicine. Some provide transportation and support for medical appointments. Other caregivers may help with finances or finding information about the cancer diagnosis.

Keep in mind that caregiving can be a long-term commitment. At times, your loved one may require intensive care. At other times their needs may be minimal. As your parent moves through the treatment experience, their needs may change. With this, your caregiving responsibilities may also change.





BALANCING CAREGIVING WITH OTHER RESPONSIBILITIES

Serving as a caregiver for a parent can come with new responsibilities and challenges. Even with these new tasks, you may have to juggle other roles and relationships in your life.

You may be:



**A spouse or have
your own children
to take care of.**



**Dating or
navigating new
friendships.**



**Navigating school, your
career, and professional
relationships.**

Through all of this, it may be hard to care for yourself and tend to other parts of your life that are meaningful.

Prioritizing your needs and other responsibilities is important. Try to identify what can be done to find balance. Some days it may feel like it is selfish to take time and care for yourself. That is not the case! **By taking care of your own needs, you can better support your loved ones through this experience.**

Try not to be too self-critical. Do not expect that you will do everything perfectly or get things right on the first try. Seeking and accepting help from other people or supportive services when you need it can lessen the strain. With reliable information, practical guidance, and support, you can feel more control over your situation.

NAVIGATING RELATIONSHIP CHANGES

When caring for a parent with cancer, you may feel that the roles have reversed. This may lead to changes in your relationship. Sometimes change can lead to new stressors or areas of disagreement.

Some ways to help navigate relationship changes, include:

- **Remaining respectful of your parent's decisions and wishes.** Allowing them to remain a part of the decision-making process, if they wish, is key.
- **Openly sharing your thoughts, feelings, and worries in a respectful way.** Every relationship is different. Some people may find it easier to disagree and talk with their parent, than others. If your relationship with your loved one is not as close, consider having a neutral person facilitate discussions between each of you.
- **Seeking and accepting support from a professional, when needed.** Trained professionals can help you identify new ways of coping and adapting to these changes in your relationship.
- **Prioritizing moments where you can spend quality time together.** Consider activities that bring you both joy. Making time for moments of positivity and connection can be a sense of relief from all the stress.

THE IMPORTANCE OF SHARED DECISION-MAKING

At times, you may need to provide support through the decision-making process. In fact, your parent may appoint you as the primary decision-maker. Some decisions may be related to their treatment and care. Other decisions may be more personal. For example, you might be asked to make decisions about their finances or housing. These may be difficult decisions and discussions that you now need to address.

Being an active member in the decision-making process is key. This ensures any questions or concerns you or your loved one may have get addressed. Open communication with your loved one will be necessary. This helps to ensure that you are both on the same page and know what to expect.



ENCOURAGING COLLABORATION

The decision-making process can be emotional and challenging at times. This may be the first time you learn about a parent's medical or financial history. It may also be the first time you have to address their physical and mental health needs. There may be times when you disagree with one another. Even if you have the best intentions, what you want may differ from their personal goals and values.

To address these challenges, try to take a supportive approach. Research and present information or different options to your parent. Then have an open discussion. This allows you both to be involved in the decision-making process. If you both still do not fully agree on a decision, continue the discussion. Strive to come to a mutual agreement for an alternative or "back-up" plan, if necessary.

If you need support, know that there are professionals that can help. Talk with a social worker, nurse navigator, or patient navigator. Their role is to help you both through the treatment and decision-making processes. They can get you connected to the right care and resources at the right time.

SUPPORTIVE SERVICES

Here are examples of services that can support you and your loved one:

Respite care provides a short break for caregivers. Trained professionals can provide care for your parent and give you the time to rest and recharge. This type of care can be arranged for a few hours or up to several weeks. It can take place at home, at an adult care center, or in a healthcare facility.

Assisted living is a type of residential community. Older adults receive daily support based on their personal care needs. This type of support allows your loved one to maintain some level of independence and reside in a home-like setting.

Palliative care is a type of supportive care for patients. It addresses any physical, social, emotional, and spiritual concerns during treatment. The palliative care team anticipates and helps manage difficult symptoms, pain, and side effects.

Hospice care is another type of supportive care for patients. It focuses on your loved one's comfort, pain management, and quality of life. During hospice care, active cancer treatments are stopped. This type of care ensures dignity and peace for both patients and their families.



To learn more about the different types of supportive care options, read CSC's resource on ***Understanding Supportive Care***.

PLANNING AHEAD

Learning about your parent's cancer diagnosis and navigating treatment can change the way you think about things. You both may begin to make different choices than you did before. It is also common to have thoughts or concerns about the future. This may include your parents' physical health, emotional well-being, and end of life concerns.

Planning ahead can help you and your parent feel more in control during this time. This includes making sure any legal documents are in order. Advance care planning is the ongoing process of making decisions about what a person wants their care to look like. These decisions are usually communicated through the following:



Will – a document that plans for how a person's money or property will be handled. It identifies any legal guardians for children under the age of 18. It also includes details and plans for any pets.



Living will or advanced directive – a document that details the patient's wishes about medical treatment if a time should come when they can no longer express their wishes and/or choices.



Health care proxy or medical power of attorney – a document that allows the patient to name a trusted person to make decisions about their medical care if they can no longer do so.



Financial power of attorney – a document that names a trusted person who is able to make financial decisions and payments for the patient's health care needs if they are unable to do so themselves.



Do Not Resuscitate (DNR) – an order the doctor writes on the patient's chart if they do not want any action taken in the event of a cardiac or respiratory arrest. The order says that the patient does not want to be put on machines that will keep their body alive. This allows for natural death.

Be sure to talk with the care team if you or your loved one have any questions. They can be a source of support to help you complete these documents.





COPING WITH STRESS & THE EMOTIONAL IMPACT

The stress that comes with navigating the cancer experience can lead to a variety of emotions. You may feel frustration, anxiety, sadness, and even denial. At times, you may feel like you have too many responsibilities between caregiving and your everyday life. It may also be difficult to see a parent sick or in need of help. This can be especially hard if they do not want to accept any help.

This experience may impact your mental health. It may even worsen any already existing mental health concerns. Remember that your mental health is as important as your physical health.

As a caregiver, be sure to make time to reflect on how you are feeling and coping as things change. Stress, worry, and other emotions are part of the journey. Everyone copes in their own way. Think about how you cope when things become challenging or stressful. Explore ways you might develop healthier coping strategies to support your mental and emotional well-being.

To maintain your mental health as a caregiver, try:

- 1** Identifying your support network—keep in mind friends and loved ones you can reach out to and talk with
- 2** Asking the cancer care team if there are resources or support groups available for caregivers
- 3** Connecting with a support group, therapist, social worker, and/or community or spiritual leader to talk with about your experiences
- 4** Seeking out services, like respite care, if you need a short break from your caregiving tasks
- 5** Engaging in exercise, meditation, or yoga – this can provide you with physical and emotional relief
- 6** Connecting with other caregivers to exchange ideas and coping strategies on CSC's Caregiver Support discussion forum through **MyLifeLine.org**

RECOGNIZING AND MANAGING CHALLENGING EMOTIONS

Be aware when emotions such as sadness or anxiety persist over time. You may also experience other difficult and surprising emotions, like anger, resentment, or guilt. Being mindful about when these emotions begin to impact your daily life is key.

While these feelings are common, it is important to seek support from a mental health specialist or social worker. Ignoring these feelings may lead to isolation and further issues. After some time, these feelings can make it more difficult to support your loved one. Seeking support from an expert early on can give you the tools to problem-solve, prevent symptoms from worsening, and get to a better place.

To learn more about Coping with Mental Health Concerns, visit www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns.



NAVIGATING GRIEF

Serving as a caregiver for a parent can lead to feelings of grief and anxiety. Grief is a reaction to losing something important or valuable to you. One of the most significant times a person may experience grief is after the death of someone in their life. However, people grieve for many other reasons throughout the caregiving process.

You may grieve the decline of your loved one's health. You may grieve changes in your relationship or feelings around losing your identity. You may also grieve after having to take time away from work or changes to your typical routine.



CSC's resource on ***Navigating Grief as a Caregiver*** can be a source of support as you move through this process.



COPING WITH A “NEW NORMAL”

Life may look very different after a cancer diagnosis. When your parent is diagnosed with cancer, you may need to develop a “new normal.” This means placing the reality of cancer and any follow up care into your future plans and goals. You may have to adjust your goals to fit the present situation. As things change, your new normal may also change.

When this happens, remember to pace yourself. Be sure to carve out time to manage your own needs and responsibilities.

As you navigate this experience, also remember to:

Keep up with your own health needs.

Let your own doctor know if there are any changes to your physical or mental health. Setting time to care for yourself will greatly benefit your loved one, as well.

Do your best to eat regularly and get enough sleep.

Try to stay physically active as well, even if that means taking a 15-minute walk. This can help you manage stress. It may take time, so try not to judge yourself harshly. You are doing the best you can with the resources you have. And that is enough!

Find balance and focus on one goal or task at a time.

It can be overwhelming to think about adding more tasks to your already full plate. Taking time for yourself and setting priorities can help you regain some control.

Think of creative ways to maintain a sense of normalcy.

Finding ways to prioritize the things that bring you joy is important. This can also help with maintaining your individual identity. While caregiving for your loved one may become a large part of your life, do not let it become the sole focus.

Accept your limitations and ask for help when needed.

As a caregiver, you have so much to manage. There is only one of you. And you cannot do everything by yourself. Accepting limitations does not mean you are letting other people down. It is okay to have others help where they can.



Stay connected to others. Share your feelings with people you are comfortable with, you trust, and are important to you. Talking with a counselor or therapist can help you cope with distress, anxiety, and depression. Joining a support group with others going through similar experiences can also be a big relief.

Caregivers play such an important role in the cancer experience. While this role can be rewarding, the responsibilities can often be stressful and take up a great deal of your time. Caring for a parent with cancer adds another level to this unique experience. Adjusting to this new reality can be overwhelming.

Try to remain patient and gentle with yourself and your loved one during this time. While caregiving may be complicated, it is important to keep the bigger picture in mind. Remember to stay focused on what truly matters. Prioritizing your own needs and wellness will also help as you support your loved one throughout this experience.



CAREGIVING RESOURCES

Cancer Support Community

888-793-9355 | www.CancerSupportCommunity.org/Caregivers

National Alliance for Caregiving

202-918-1013 | www.Caregiving.org

Caregiver Action Network

855-227-3640 | www.CaregiverAction.org

Family Caregiver Alliance

800-445-8106 | www.Caregiver.org

National Cancer Institute

800-422-6237 | www.Cancer.gov

MENTAL HEALTH RESOURCES

Cancer Support Community

888-793-9355

www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns

www.CancerSupportCommunity.org/Coping-Grief-Loss

National Alliance for Caregiving

202-918-1013 | www.Caregiving.org

National Alliance on Mental Illness

1-800-950-NAMI (6264) | www.NAMI.org

American Cancer Society

800-227-2345 | www.Cancer.org

MentalHealth.gov

www.MentalHealth.gov

National Cancer Institute

www.Cancer.gov/About-Cancer/Coping/Feelings

National Suicide Prevention Hotline (U.S.)

800-273-8255 or 988

Substance Abuse and Mental Health Services Administration

1-800-662-HELP (4357) | www.SAMHSA.gov

CANADIAN MENTAL HEALTH RESOURCES

Suicide Prevention Service - Canada

833-456-4566 or text 45645

Hope for Wellness Helpline - Canada

1-855-242-3310 | www.HopeForWellness.ca

Wellness Together - Canada

text WELLNESS to 741741 for immediate crisis support



Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 196 locations, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more:
www.CancerSupportCommunity.org/Find-Location-Near-You.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/Become-Advocate.

This publication is available to download and print yourself at www.CancerSupportCommunity.org/Caregivers

For print copies of this publication or other information about coping with cancer, visit Orders.CancerSupportCommunity.org

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