

Navigating Grief as a Caregiver

CANCER CAREGIVERS

Helping the Helper

Frankly Speaking About Cancer

Taking care of someone with cancer can be a rewarding experience. It can also be challenging at times. One challenge of caregiving is navigating grief. Grief is the reaction that occurs after experiencing a loss. People grieve for many reasons. It is not only limited to the physical loss of a person. Grief can also arise when you anticipate loss. This can be the loss of a relationship or future plans. Everyone experiences grief differently. It is a normal part of life and the caregiving experience.

This resource explores what grief is and what you can expect during the grieving process. It provides insight into ways to cope with grief and resources for support.

WHO ARE CAREGIVERS

In this resource, the term caregiver describes anyone who provides or arranges help for a person with an illness or health concern. This type of help can be physical, emotional, spiritual, financial, or logistical. A cancer caregiver is anyone who provides support and informal care to someone diagnosed with cancer. Additionally, the term “loved one” is used here to describe the person diagnosed with cancer. This could be someone with whom you have any type of relationship and are assisting with their care needs.



WHAT IS GRIEF

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. How you experience this grief may depend on your relationship and how close you were with that person.

It is important to note that everyone experiences grief differently. This is because the meaning of loss varies greatly from person to person. How you experience grief may also depend on your cultural background and your beliefs regarding life and death.

People grieve for many other reasons throughout the caregiving process. For example, you may grieve the decline of a 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 daily schedule. Many people grieve after having to put future plans and goals on hold. The feelings you may experience of loss and grief are normal.

What To Expect When Grieving

While grieving, you may feel many emotions. You may experience feelings such as shock, denial, sorrow, and anger. You may also feel resentment, guilt, numbness, and even relief. Learning about the grieving process can help prepare you for loss. It can also make you aware of when to seek help, if you need it.

During this process, you may find yourself moving through various emotions. One day you may feel joyful and hopeful while the next day you may feel anxious and tearful. Dealing with these emotions is a normal part of the grieving process. Even after some time has passed, a variety of emotions can reappear unexpectedly. This can be in response to a memory, a song, special date, or an experience that reminds you of the loss. It may be confusing to experience such a wide range of emotions or to feel them with such intensity. Over time, you will gain more insight into these feelings. You will learn how to acknowledge your loss and the emotions you are facing.



Grieving is not only an emotional process. It can affect a person on a physical, cognitive, behavioral, and spiritual level. You may experience trouble sleeping, fatigue or a lack of energy, and changes to your appetite. You may also have trouble concentrating or remembering things.

These symptoms are also normal. They should gradually become less intense over time. However, if you or a loved one notice that these symptoms are persisting, getting worse, or interfering with your daily life, seek professional support.



Caregiving for someone can elicit strong emotions. It is important to reflect on how you are feeling and coping as things change. Using alcohol, cigarettes, and other substances to numb your emotions is not a healthy way to cope. If you are experiencing any concerns, behaviors, or feelings that you need help navigating, there are many resources available to you:

ONE-ON-ONE THERAPY: Allows you to meet with a licensed therapist, psychologist, or counselor to discuss any concerns. Sessions typically last 60 minutes and can be done in-person or virtually.

GROUP THERAPY: Group therapy is usually led by a professional such as a therapist or psychologist. Everyone in the group has similar needs and can benefit from each other's support.

SUPPORT GROUP: These groups offer peer support. You can learn about additional ways to cope from others in similar situations. These groups may be led by a clinician or other facilitator.

HELPLINE/HOTLINE ASSISTANCE Helplines are typically associated with support organizations. Calling a helpline can give you additional resources appropriate for you and in your area.

This is not a “one size fits all” model. If one option does not work for you, do not give up. There is beneficial support out there for everyone. These options may also be offered within your loved one's care center or at an outside provider.

You can also refer to the end of this piece for a list of trusted organizations. CSC and other organizations have helplines, support groups, and other resources to assist you and your loved ones.



Navigating Anticipatory Grief

As a caregiver, you may experience different types of grief including anticipatory grief. This occurs when a person is expecting or preparing for a loss. It is normal to experience this type of grief after a major life change occurs, like a cancer diagnosis. You may begin to think about how you would cope if you lost your loved one due to their diagnosis. You may also anticipate the loss or change in your relationship, as you move towards the caregiver and patient dynamic.

The emotions you feel during this time can be just as intense as if the loss already happened. For example, you may experience increased irritability, sadness, and anxiety. You may also feel a heightened sense of concern for your loved one. Even though you may anticipate these losses, you may not be fully prepared for the emotions that arise after an actual loss occurs. In addition, it is important to recognize that anticipatory grief is unique. While you are feeling these emotions, you may also feel hopeful. There is still hope that your loved one will live a long time and survive their diagnosis.

MYLIFELINE®

Cancer Support Community's private support community website that connects cancer patients and caregivers with friends and family, and others like them, through discussion forums and private sites with an interactive blog and calendar to manage practical support and events.

To learn more, visit **www.MyLifeLine.org**.



Navigating Mental Health & Complicated Grief

Navigating a loved one's cancer diagnosis already brings a variety of emotions. Experiencing grief on top of this can significantly impact a person's mental health. It can even worsen already existing mental health concerns.

Mental health involves your emotional, mental, and social well-being. At times, mental health challenges may be diagnosed as a mental illness. This could be when the challenges begin to affect a person's thinking, feelings, behavior, or mood in a way that makes it difficult to accomplish daily tasks.

It is important to 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. Think about how you cope when things become challenging or stressful. Then consider ways you may want to improve or develop more healthy coping skills.

Some people have a very hard time adjusting to their loss. During this time, the grieving process remains intense, or worsens, and begins to impact daily life. This heightened state is called **complicated grief**. Feelings of depression, anxiety, a persistent sense of regret and guilt, and thoughts of suicide may occur. Complicated grief can keep you from fully healing and coming to terms with the loss.

In this case, it is important to seek support from a mental health specialist or social worker right away. Ignoring these feelings may lead to isolation and further concerns. Seeking support from an expert is essential. They can help 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.

988 SUICIDE HELPLINE

This is the dialing code for the U.S. National Suicide Prevention Lifeline. Those in the U.S. can call, text, or chat 988 to connect with trained counselors. This is free and confidential support for those in suicidal crisis or emotional distress. Visit 988LifeLine.org for more information.

People in Canada can call the Suicide Prevention Service at 833-456-4566 or text 45645 between 4pm and midnight to connect with a crisis responder.

These are free resources for mental health and crisis support.



COPING WITH GRIEF

After experiencing any type of loss, it is important to take the time to mourn. There is no “right” way to grieve. There is also no set timeline for this process. Some people move through grief slowly, while others may move more quickly.

If you are grieving, there are things you can do to take care of yourself. Try to:

Think about what you can do to take care of your physical health: Taking a walk, getting rest, minimizing alcohol, and eating well can help. These actions will give you the physical strength needed to manage the emotions you are feeling.

Give yourself permission to take a break from your sadness: It is okay to laugh or have fun. Doing the things you enjoy may help relieve the stress and tension that accompanies grief.

Relax your expectations of yourself: Be patient and give yourself grace. You may not be able to accomplish and manage all the things you are used to doing, and that is OK.

Remember that everyone goes through this process in their own way and at their own pace: Again, there is no “right” way to grieve. Your process will likely look different than that of friends or family members who are also grieving. Take your time and do not feel pressured by others to rush your own process.

Be honest with yourself and others about how you are feeling: Embrace your emotions. Being open about how you are feeling can empower you as you navigate the grieving process.

As you grieve, try to recognize the ways that you might be growing or becoming stronger. Some people who experience loss become closer to family or friends, have a new appreciation for life, or gain new perspectives. You may be surprised by what comes out of or follows your grieving process.

CANCER SUPPORT HELPLINE® If you need help finding resources or want help getting information about cancer, call CSC’s toll-free Cancer Support Helpline® at 888-793-9355. It is staffed by community navigators and resource specialists who can assist you Monday - Thursday 11:00 a.m.- 8:00 p.m. ET and Friday 11:00 a.m.- 6:00 p.m. ET.



MENTAL HEALTH 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.

www.CancerSupportCommunity.org

National Alliance for Caregiving

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

www.WellnessTogether.ca | text WELLNESS to 741741 for immediate crisis support

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

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 nearly 200 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched 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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