Understanding Grief:
A Guide for Grieving Caregivers

From Right at Home®
With the Expert Advice of Dr. Eboni Green*

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Understanding Grief ...

Anticipatory Grief

Grief is not exclusively tied to mortality. In fact, it is not uncommon to grieve prior to the death of a loved one. With anticipatory grief, you may experience some measure of hopelessness, guilt, anger, denial, fear, confusion and sometimes even rage, but not readily associate these emotions with your sorrow. This is especially true for caregivers, as you have likely been adapting to multiple losses. These losses are often attributed to managing the changing care needs and/or unpredictable nature of your loved one’s disease. Here are seven tips for coping with anticipatory grief:

7 Tips for Coping
When Someone You Love Is Nearing the End of Life

1. Make sure your loved one’s wishes are documented and followed.

Most people nearing the end of life are not physically, mentally or cognitively able to make their own decisions about treatment. As a result, advance care planning is essential to ensure that your loved one receives care that reflects his or her values, goals and informed preferences. Should the opportunity present itself, take time to ask and then document your loved one’s care preferences. If you feel uncomfortable asking questions about care preferences, reach out to your loved one’s healthcare team.

2. Make sure that nothing is left unsaid.

Express your feelings with your loved one who is passing, even if you think he or she cannot hear you. Hearing is among the last senses to go. Some caregivers take this opportunity to write a letter so it can be read by your loved one or read aloud at the bedside. Others prefer to verbally express their love spontaneously. There is no one approach to communicate your feelings. What is important is that you do what works for you and your loved one in the moment.

3. Be a good listener.

It is important to be a good listener. Allow time for your loved one to express his or her feelings. Be present and acknowledge when you do not have the answers to complex questions or concerns. In the case where you do not feel prepared to address specific questions, reach out to clergy or your loved one’s healthcare team.

4. Don’t be afraid to express your sadness.

Losing someone you love is emotionally taxing and you will not know how you will react until your loved one passes away. Raw emotions are warranted when there is a significant loss. It is OK to express your sadness, as holding in or suppressing your emotions is unhealthy.

5. Be aware that everyone processes their sadness differently.

Everyone hurts but expresses their sadness in a unique manner. One of the biggest challenges is to acknowledge that some family and friends may not be as supportive as you think they should be during this stressful time. It is likely that what most grieving individuals need are patience and understanding, as they may not be thinking through everything they say or do. They also may not remember everything being said or done during this time frame; therefore, understanding and patience are important.

Caregiver Support Services. End of Life Quiz.
http://www.caregiversupportservices.com/Caregiver_Help/End-of-Life_Quiz/
You have lost someone you love and you are not sure how you will cope. Until now, caring for your loved one has been your priority. In fact, you may have had little opportunity to recognize and address your feelings of sadness. Identifying positive coping and self-care strategies now is the priority as you work to address your grief. Know that you most likely will not follow the same pattern as others when dealing with your loss, so do not be burdened by unrealistic expectations on how to address your sadness. The following are three common myths about coping with grief:

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<th>Myth #1 - The goal of grief work is to find closure.</th>
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<td>Not everyone will follow the same pattern of coping with grief, and because there is not a set process, you may have unrealistic expectations regarding grief. Therefore, be cautious of the suggestion that the goal of processing grief is to work through its stages and that the result is closure, as this is simply not true. The truth is that losing someone you love changes your life forever, and though you will likely not get over your sadness, it is possible to learn to cope.</td>
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<th>Myth #2 - There are five stages of grief.</th>
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<td>While it is true that Kübler-Ross's conceptualized grief model based on directional movement through grief is popular, what is often overlooked is that Kübler-Ross's very meaningful work focused on improving the care of individuals nearing the end of life. In fact, her direct interviews with individuals who were dying transformed the way we care for individuals nearing the end of life, but only loosely relate to those who are living and grieving. So rather than focusing on the stages of grief, you may find that outlining the emotions associated with grieving the loss of a loved one is purposeful to identifying these feelings as normal and understanding that you are not alone.</td>
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<th>Myth #3 - Grief is a condition that should be treated.</th>
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<td>It is normal to experience intense sadness after losing someone you love. Yet, even when you are sad, it's possible you will generally maintain the ability to feel pleasant emotions, and you probably will retain the ability to find meaning in your life. In fact, over time, you will begin to establish a new equilibrium so you can resume normal activity. Even though you may feel like you will be overpowered by your sadness from time to time, it is not pathological to be heartbroken.</td>
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6. Don’t be alarmed if you feel some measure of relief when your loved one passes.

Relief may be felt about the end of the suffering of a loved one if the illness was long and painful. You may find that you also feel guilty for feeling relieved. Guilt can be exhibited through resentment, anger, sadness, hopelessness, lashing out verbally and other unhealthy behaviors. To work through your guilt, you might discuss your loved one's disease process so you have a better understanding of the underlying medical conditions. Rather than focusing on the negatives, try to spend time reflecting on the positive experiences you have shared.

7. Take care of yourself.

Self-care is vital to your well-being while you are grieving. You may have trouble sleeping or you may overeat or not feel like eating at all during this stressful time. That is normal. However, it is important that you do not end up depleted. Should you find you are having trouble eating or sleeping, you might consider taking a nap when you can or eating several smaller meals throughout the day and drinking at least eight eight-ounce glasses of water. Also, consider getting a medical checkup because grief can impact your health. You may also find the “6 Strategies for Self-Care While Grieving” (page 7) helpful.
Common Feelings Associated With Grief

Common feelings associated with anticipatory and post-caregiving-related grief and loss include anger, tears and laughter, distress and anxiety, emotional and social isolation, depression, and guilt and regret.

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<th>Identifying Your Feelings</th>
<th>Suggestion for Coping</th>
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<td><strong>I feel that I am all alone.</strong></td>
<td>Determine the source of your emotional or social isolation. Have you distanced yourself from your family and friends in an act of self-preservation and are you now feeling as though you might want to reconnect? If your goal is to reconnect, be sure to express your need for support. Having access to your family and friends for support can restore a sense of balance, as other family members may also be feeling distressed. In fact, being understood by family and friends in an empathetic manner is what most individuals who are grieving find comforting. If you are seeking support but have a diminished pool of family and friends on which you can depend, you may decide to spend time in a public space where you can meet new people. Perhaps there is a coffee shop, library or grief support group that you can attend where you can meet and connect with others.</td>
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<td><strong>Identifying Your Feelings</strong></td>
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<td><strong>Perhaps you are experiencing social or emotional isolation.</strong> Social isolation refers to the lack of support from family and friends, whereas emotional isolation is often used as a coping mechanism. With emotional isolation, you may have supportive family and friends who are readily available, but you choose to be left alone. Some individuals need space to process their loss and the feelings associated with the death of a loved one. When you experience emotional isolation, your life may feel empty even when you are surrounded by people. Emotional isolation can include a loss of interest in the outside world for a short period of time that usually corrects itself.</td>
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<td><strong>This situation is totally unacceptable in my heart.</strong></td>
<td><strong>Suggestion for Coping</strong></td>
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<td><strong>You might be angry.</strong> Anger is often the first tangible feeling that you experience after losing someone you love. You may feel numb and then all of a sudden notice that you are, in fact, angry. It is OK to be angry; actually, a certain amount of anger is considered healthy. The type of anger experienced during grief usually does not preclude you from experiencing positive feelings. When your anger goes unchecked, it can lead to complicated grief; therefore, when anger leads to unhealthy behaviors, it is important to find the deeper meaning behind your anger.</td>
<td>One of the best ways to release negative energy, like anger, is to participate in regular physical activity. However, with grief, there may simply be things that have gone unsaid that need to be expressed, and there are likely other feelings hidden beneath your anger that must be addressed. Writing an open letter and reading it out loud and in its entirety, without interruption, can work to diffuse your anger. You may choose to read it alone or with someone you trust and then discard the document as a symbolic way of letting go of the negative energy.</td>
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<td><strong>I find that I wax and wane between laughing and crying.</strong></td>
<td><strong>Suggestion for Coping</strong></td>
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<td><strong>Tears and laughter can be normal responses to grief and can result in a release of tension.</strong> You have probably experienced a variety of losses while caring for your loved one; some losses may have occurred while your loved one was in your care, whereas others resulted from the unpredictable nature of the situation.</td>
<td>Give yourself permission to experience an emotional release, reach out for support from family and friends, and seek the assistance of a professional grief counselor should you find that you need help in working through your grief, with the goal being emotional resolution.</td>
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### Identifying Your Feelings

**Perhaps you are feeling guilty.** Guilt is defined as contradictory internal feelings resulting from thoughts about what could or should have been done to support or care for your loved one. It is not uncommon to question the decisions made while providing care for a loved one. Questioning may occur even when you know you have done all that you could. Most guilt does not stand up to the “reality test,” which means if you were to think about the care you provided for your loved one, you would come to the conclusion that you did all you could.

**Identifying Your Feelings**

**You may be experiencing depression.** Depression can be described as an exaggerated hollow feeling often marked by hopelessness and a sense of self-doubt. Fatigue, insomnia, troubled sleep and other physical symptoms are possible indicators of depression. Depression is frequently experienced during the first year following the loss of a loved one. It is normal to experience such extreme sadness when there is a significant loss.

**If I were to think about my loved one’s passing, I would not handle it well emotionally.**

**Perhaps you are emotionally distressed.** For a time, you will likely feel worried, overwhelmed, restless and tearful; have trouble sleeping; and find that you are overeating or undereating. Anxiety is an extreme response to grief. Symptoms can include difficulty with concentrating, poor decision making and reduced enjoyment, and anxiety may cause you to view difficult situations as threatening.

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### Suggestion for Coping

**Should you find that your guilt is unresolved, you might consider writing down the name of the person or persons toward whom you feel some level of guilt. Beside each name, write down what action or behavior makes you feel guilty. What feelings arise when you think about the person or event? Next, make a note of how long you have felt this way. Finally, search your soul for a way to forgive yourself, even if it just means acknowledging your human spirit. Then practice the act of forgiveness as best you can and let go of your guilt.**

**Talk openly with your doctor or someone you trust regarding your physical and emotional symptoms so you can determine if they are related to your grief. Should you determine that you are, in fact, depressed, it is vital that you find professional counseling and care. Please do not feel afraid to seek this out.**

**Identify your biggest triggers.** Recognize that you may have had little time to adjust to the demands of caring for and then losing someone you love. Managing the anxiety associated with having provided care can be complex. It is essential to identify your greatest triggers for anxiety, so while you are healing, you can avoid activities that will only serve to intensify your feelings. Other possible strategies for working through anxiety include meditation, deep breathing and head-to-toe body relaxation exercises. Some find that listening to calming music or just stepping away from an intense situation for a moment can reduce immediate feelings of anxiety.
Guided Breathing and Imagery Exercises

Guided Breathing Exercise

Focusing on your breathing can be an effective strategy to release your distress. You can practice it in almost any setting. Should you feel overwhelmed, deep breathing can help you refocus.

- To begin, sit up straight in your chair, making sure that your back touches the back of the chair while your feet are planted squarely on the floor.
- Next, place your hand on your diaphragm and take a deep breath in, hold the air in your lungs for about three seconds, then slowly with your lips pursed release the air ... three, two, one.
- You may repeat this practice several times until you are fully relaxed.

Guided Imagery Exercise

Guided imagery is another approach you might find helpful when you are overwhelmed with feelings of grief. Please try the following guided imagery exercise:

- Close your eyes for a moment and imagine that you are in an open field. The sun is shining brightly, however, it is not hot, because there is a steady breeze. In fact, the field is filled with your favorite flowers and they cascade in synchrony—a motion you find relaxing. You locate a clearing in the midst of the field, a place that is uniquely comforting to you. You take a moment to sit down and release any and all feelings of sadness. When you are ready, you slowly stand up and leave your burdens in the clearing. You slowly walk back through the field, touching the tops of the flowers with your fingertips. Each flower you touch brings you healing, and you find that you are increasingly relieved of your once-heavy sadness. When you are ready, open your eyes and you are revitalized.

Journaling Exercise

Journaling is an effective strategy for working through your grief. The following questions are for you to ponder and serve to document your feelings. You do not have to address all of the questions in one sitting. In fact, you are encouraged to take your time and address each question when you have the ability to fully think through each one.

- How would you describe your relationship with your loved one?
- What impact does your loved one have on your life?
- How can you incorporate your loved one’s best attributes into your daily life?
- What obstacles are you facing right now as you are grieving?
- What steps can you take now to strengthen your ability to face your sadness? Who might you reach out to for help?
- How can you use what you are learning about your grief?
- Are there any resources that will enhance your ability to cope?

Now that you have had the opportunity to journal your feelings, be sure to incorporate constructive strategies for coping and acknowledge the positive impact that your loved one had in your life.
Strategies for Self-Care While Grieving

Should you find that you are more than just sad, that you are caught off guard by the intensity of your feelings, or that you are simply unable to cope with your emotions, you might be experiencing more than extreme sadness. Ambiguous, complicated grief and post-traumatic responses should be approached with seriousness. Once identified, they should be addressed immediately.

1. Make sure you are getting adequate sleep.

Many caregivers, especially in the early days of their grief, find that they are having trouble sleeping, which can lead to a confused state of mind, including rambling thoughts. You might find that you are sleeping too much or too little, or that you are still feeling exhausted even when you have had adequate rest. Without quality sleep, it is not possible to heal. You need sleep because sleep revitalizes you. If you find you are having trouble sleeping, try natural ways to improve your sleep, for example, listening to relaxing music, reorganizing your day so you are able to wind down, and decreasing your caffeine intake during the day. Should these strategies fail, speak with your doctor.

2. Participate in regular physical activity.

Schedule adequate time for physical activity, as participation in a regular exercise routine is not only healthy, but it also helps with reducing stress. If you need to increase your physical activity, you might consider going for a walk, getting a gym membership, or even using an exercise video. Please make sure you check with your doctor prior to starting any new exercise program. It does not matter which activity you choose, it is only important to make sure you are taking time out for regular physical activity.

3. Maintain proper nutrition.

Eating a well-balanced diet is essential to coping. Skipping meals or overeating can impact your health and well-being. When you eat, take time to sit and enjoy your meals. Avoid snacking on commercial snack food; instead, try fresh fruit and vegetables. If you need nutritional assistance, seek advice from a professional nutritionist.

4. Listen to what your body is telling you.

Are you feeling tired all the time, experiencing aches and pains, or walking around with your stomach in knots? Listen to your body. Perhaps it is trying to tell you something. In time, you could find that suppressing your feelings is impacting your overall health. Should your symptoms persist, reach out to your doctor.

5. Express your feelings of anxiety or stress with a pastor or close friend, or consider joining a grief support group.

Whenever possible, try to express your feelings as they arise. Do not hold in your emotions. Try talking to a close friend or your pastor, or join a support group. It is important that you do whatever works best to make your situation better. Over time, having expressed your feelings will be better for your personal well-being.

6. Seek professional counseling services.

If you feel overwhelmed by your feelings, seek professional counseling and care. The goal is to work through the unfinished business of exploring the painful trauma associated with your grief so you can heal. Remember that getting in tune with your sadness will not destroy you. To the contrary, it may afford you the opportunity to work through your sadness in a controlled manner so it does not resurface in an unhealthy manner later down the road.

Initially, it may be challenging to express your feelings with others; however, over time, you will find that having received the support you needed was extremely beneficial.
Right at Home is here to help you with in-home caregiving and grief resources in your area.

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