

DisabilityCampaign.org

Comfort for the Grieving Caregiver



Caring for someone else's needs is a tremendous responsibility. For many caregivers, it means years of dedication to a loved one who is ill or disabled. As with any relationship, it's likely that through the months or years, memories were formed, sacrifices were made, expectations evolved, and perseverance was tested. And though we all know that someday our loved ones will pass away, the concept of death may be more imminent for caregivers than for others. When a loved one dies, all kinds of emotions may be experienced by the grieving caregiver — from sadness, to regret, to relief. What's more, with that passing of a loved one can come the feeling of a loss of one's "identity" as a caregiver. It's why, if you are currently mourning, we hope that this resource will help you cope as you navigate this new stage of life.

Mourning before death

Long before a loved one dies, caregivers may begin to experience what is called “anticipatory grief.” With a disability or chronic illness can come changes — not only to the health and abilities of your loved one, but also to their role in the home, as a provider, or in your relationship. As a caregiver, you may feel as if though you’ve already “lost” your relative or friend even though they are still living.

Caregiving is tough, often asking the most of your strength and time. For some it can feel so overwhelming, that the thought of their loved one passing away can bring on a sense of relief. It’s not that you wish your parent or husband would die; rather, it’s a hope that the day-to-day responsibilities would end and that your loved one’s suffering would cease.



If you are experiencing this type of grief, it’s important to understand that these feelings are normal and common. Still, that doesn’t mean you have to deal with anticipatory grief on your own. While you may not feel comfortable expressing such feelings to your disabled loved one, it’s important that you talk about them with a professional counselor or therapist.

Mourning at death

No matter how prepared you may feel — whether that be emotionally, financially, or mentally — the death of a loved one who was disabled is a life-altering experience. There are immediate needs that must be addressed, such as contacting family members, arranging funeral preparations, or speaking to your financial advisor. And throughout all of this, you are trying to manage the flood of emotions that the death of your loved one has brought on.



Perhaps you may also find yourself feeling lost now that you have no one to care for on a regular basis. What do you do now that you don't have to worry about your husband's doctor's appointments or give your mother bed baths? What's more, if you cared for your relative in your home, you may find that accessible features like your front door's ramp or your bathroom's grab handles are constant reminders of the loss you're experiencing.

As you can probably tell, grief is often experienced over an extended period. And how it manifests itself will vary from person to person, sometimes depending on religion, life experiences, or cultural background.

How grief manifests itself

Some people view grief strictly as an emotion you *feel*, but the truth is grief can manifest itself in a variety of ways — including physically and socially. Emotionally or mentally, a person can experience crying spells, rage, worry, a sense of lack of control, memory problems, edginess and guilt. But physically, you may find yourself fatigued, with headaches, stomach pain, changes in appetite, and sleeping problems.



Social symptoms include isolating oneself or not wanting to be alone, feeling uncomfortable in large groups, or feeling detached from others. Some people also struggle with their faith or system of belief, whereas others may find themselves delving deeper into spiritual guidance to find consolation.

The Five Stages of Grief

The process of grieving is complex, and everyone goes through it differently. Still, many of us experience these five common stages of grief, as defined by renowned psychiatrist, Dr. Elizabeth Kübler-Ross. It's important to note that these may not be experienced in a linear progression and that not everyone experiences each stage.



- **Shock or denial.** You may struggle with accepting a diagnosis or death. You may feel “numb,” as if though you are going through the motions or struggle to do usual activities.
- **Anger.** The anger could be geared towards yourself, the person for whom you care, physicians, the health-care system, God, your faith, or life itself. Some people may bottle up this anger, whereas others may demonstrate it by isolating themselves or through reckless behavior, self-harm, or drug and alcohol abuse.
- **Bargaining.** This is when we think of “if only” or “what if.” We make deals with ourselves, with life, God, our families ... thinking that somehow this will change our circumstances. Most of us, however, know that bargaining will likely not bring about the quality of life we seek for our loved one.
- **Depression.** While it's common to experience feelings of sadness, loneliness, emptiness, regret, fear, and anxiety over the losses and changes associated with caregiving for a dying loved one, these feelings can develop into clinical depression. If your sad feelings are interfering with your daily living and you feel you are losing the ability to control them, or if you have thoughts of suicide, contact your health care provider.
- **Acceptance.** Eventually, with time, hope, and help ... you will adjust to your new reality and move on. This doesn't mean that you will not feel sadness, anger, or regret in the future. It means that you are now in a place of healing and that overall, you can look towards the future with a sense that things will be okay.

8 Tips to Help You Cope with Grief

1. **Give yourself permission to grieve.** The emotions you are experiencing are common. Any caregiver would struggle with the changes that come after a loved one dies, so give yourself the opportunity and the time to go through these feelings. Rather than bottle them up or try to oppress them, address the feelings as they come and go.

2. **Seek help from others** who can encourage you during this mourning process.

You cannot and should not go through this alone. Connect with friends, family, clergy, grief support groups, and professional therapists or counselors. If your loved one was provided with support through hospice or palliative care services, you can connect with those services, too, for help as you grieve their death.



3. **Take care of your health.** It's easy to get consumed in the many tasks that must be done after a loved one passes. Plus, the feelings of grief can be so overwhelming, that you may neglect your health, sleep, or diet. Make an appointment with your primary care medical provider — even if you feel “fine.” Perhaps you don't *feel* stressed, but your body may be reacting to that stress in ways you cannot see or may not sense, such as in the case with high blood pressure or elevated blood sugar levels.

4. **Be mindful** of how you're progressing through the stages of grief. Keep a journal or join a support group so that you or others can point out if you are, for example, dwelling in anger or perhaps rushing into acceptance. Also, be aware that others may not experience grief in the same way as you. This includes family members or friends of your deceased loved one.

5. **Talk with a professional.** While it's important you stay connected to friends and family, a professional therapist or counselor can provide you with a listening ear and an unbiased perspective. He or she is trained to catch early signs of depression, whereas a friend may not notice there's a problem. Plus, a therapist or counselor can provide helpful tips and coping mechanisms, as well as therapy options to help you grieve in a manner that is safe and healthy.



6. **Remove distractions.** Perhaps you were so used to being busy with caregiving routines, that now you find yourself filling your plate with volunteering, shopping, eating, etc. This can be a way of masking what you are really feeling. To reduce unnecessary stress, try to clear up your schedule and only commit to that which brings you joy and peace. Another type of distraction may be the disability-related items that are still in your home. A commode, wheelchair, or communication board can become constant reminders of your loss. When you're ready, these items can be donated or stored away.

7. **Celebrate memories.** As a caregiver, you've experienced the hardships associated with a disability. But as a spouse, child, sibling, parent, or friend to your loved one, it's likely you also have happy memories of your time with them. Cherish and celebrate these memories. Honor your loved one by donating on their behalf or by serving others affected by disability.

8. **Be thankful.** Show gratitude towards those who also helped care for your loved one.

You don't have to go out of your way; a simple thank-you card to the doctors and nurses who oversaw his or her care will do. Thank others, including extended family, neighbors, or clergy on behalf of your relative with a disability. Of course, don't forget to give yourself credit for the care you provided. You gave a lot in dedicating yourself to caring for the needs of your disabled loved one — and that deserves a standing ovation!



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