

Published on *SeniorNavigator* (<https://seniornavigator.org>)

## Grief: Understanding the Experience of Loss

### **Loss and Grief**

Bereavement, or grief, is a process that we go through in dealing with loss. Grief is usually associated with the death of someone we know, but can occur with other losses. Job responsibilities lost through retirement, key positions in church or community organizations, our physical health and capabilities, and home ownership - all can be lost. As a caregiver, we might grieve no longer having an active partner to share in the daily responsibilities. Throughout our lives, we might experience all of these complexities of loss.

Feeling grief is natural, and there is no set time for how long each of us will need to grieve. How we go through the process is as individual as we are. Our life experiences, beliefs and support systems all contribute to how we grieve. Feeling chronically overwhelmed and unable to function for an extended time period because of a loss - whether due to the death of a spouse, a divorce, or change in housing - is cause enough to seek professional help.

### **Stages and States of Grief**

Grief and loss may begin long before death, as our lives unfold differently than we had planned. The following are stages associated with how we might grieve throughout the caregiving process. An individual may go through each stage or may stay at one stage for a long time. There is no particular order and may depend on the care recipient's health, but going through the stages is a normal process.

- Shock
- Emotional release
- Depression, loneliness, and a sense of isolation
- Physical symptoms of distress
- Panic
- Guilt

- Anger
- Inability to participate in normal activities
- Regaining of hope
- Acceptance

Each stage of the caregiving experience includes losses and grief. All of these feelings are normal and may include feelings of joy and intimacy you never expected to experience. The more people you meet, who share your experiences, the more you will find they share many of your feelings as well.

## **Shock**

When someone you love is diagnosed with a chronic illness or terminal illness you might first deny the reality, that the test results must be for someone else. Even though there was a reason why the tests were done to begin with, you are stunned with the truth. Not only is the one you love facing the shock, fear and wonder of what will happen, but, as a caregiver you too face the shock, the fear and worry of what your future will be like. Everything in your life is suddenly turned upside down; any plans you have made may need to be put on hold. You go from planning to how you will live in your retirement years to how you will live each day.

## **Emotional Release**

When someone you know receives a diagnosis for a chronic or terminal illness, many thoughts may go through your mind. Once those what ifs are played over and over in your sub-conscious, the reality of how scared you are and how your life is quickly changing in an unplanned way takes over. The worry of how you will handle it all is overwhelming. While you try to be brave you may cry at any moment - in the car driving from home to work, from the hospital to school, in the grocery store line, at work in your office and at home. People meaning well, ask many questions; you are never able to forget how frightened you are. You and your care recipient are on center stage with everyone wanting to know every facet about what is happening to you. It is a difficult time.

## **Depression, Loneliness and Isolation**

After the initial shock of the news you have learned, you start to plan how to proceed. If it is an illness, a treatment plan begins. Treatment is usually not easy for either the caregiver or the care recipient. There are many doctor visits, rescheduling

of activities, the missing of significant events, and the loss of personal time. There is the pressure to stay strong and trying to be encouraging to your partner, family member or friend.

Others don't know what to say, so they avoid saying anything. Everyone else's routine goes on uninterrupted. You have no routine; you can plan nothing. You live your life based on everyone else's availability and schedules. It is easy to feel sorry for yourself at this time; it is easy to convince yourself that things will only get worse. It takes great effort to continue to do the meaningful things that are key to your life and those of your care recipient's.

### **Physical symptoms of distress**

We each cope with the stresses in our lives differently. Many of us have had opportunities throughout our lives to take major changes in stride. Others have had limited dealings with trauma and may not know what to do. Stress may cause you to become dysfunctional. Physical stress can materialize in many ways-the inability to sleep, decreased desire in eating, sadness or depression, the inability to function in normal activities, difficulty in working or focusing, or an increase in crying spells at any time.

### **Panic**

As you continue to try and plan out your life, you ponder many endings to your story. It is easy to think that things will not work out. In many cases, this may be the first time you question what will you do if your partner, family member or friend dies. You may often ask yourself 'How will I survive?' The imagined endings to the changes you are experiencing may not be happy ones; they may present very desperate changes that you really don't want to think about. As a result, panic sets in - you continually worry about what will happen to your care recipient and how you will handle each stage of their disease process.

You also think about yourself. If you are caring for your partner, who will take care of you? Who will reassure you that everything will be all right? But will everything be all right? How will your children handle this situation? Will you be able to handle the financial responsibilities? Will you need to move from where you are living? You feel that on the outside you must be very calm and very brave; but on the inside you feel very scared and very alone with these worries.

## **Guilt**

It is easy to blame yourself for what has happened. With illnesses, could diet or exercise have made a difference? Should you have insisted on going to the doctor sooner? Should you have gone to a different doctor? Should you have tried a different treatment? Should you have been more patient? Could you have done more?

Any thought you have of yourself feels selfish. You wish that you had some time to spend on yourself, and this makes you feel guilty. The guilt plays over and over in your mind. It is hard to see a partner, a family member and a friend in a situation that will not improve as is the case with chronic and terminal illnesses. Human nature does not accept loss easily; it makes us feel guilty and helpless when we cannot reverse the life continuum.

## **Anger**

When bad things happen to you, a common reaction is to be angry. You feel angry at life in general, angry because your life has changed. If you are caring for your partner, you now have all of the responsibilities that the two of you used to share. You have no leisure time, you are working harder, and you are feeling very tired. You feel pressure to get everything done at work and at home. You have no fun any more; you feel like you are doing everything poorly. You are feeling financial pressures with the increase in medical expenditures. You are frustrated that your tasks keep increasing. You are having to give up so much. And, you are angry because you are losing your partner or your loved one.

## **Loss of Normalcy**

As your care recipient becomes more and more dependent on you, your life and activities, as you previously knew them, fade away. Your care recipient becomes your life. Every waking moment of your day revolves around the care and needs of your loved one. Doctor visits and home healthcare visits become the focus of your life. You listen to every word and hope that something will change. For individuals who cherish their privacy, it is very difficult to be the center of attention. You may want to be unrecognized so that you can grieve without feeling like everyone is watching how you are handling it all.

## **Regaining Hope**

As a caregiver, small things can bring great happiness:

- a night that your care recipient slept without waking in discomfort;
- doctor visits when you were seen at your appointment time;
- doctor visits where your care recipient's condition had remained the same or had not deteriorated;
- the care recipient is able to speak after a period of silence;
- finding that others share your feelings;
- a visit from a friend who focused only on you.

Miraculously, you start taking each day at a time.

## **Acceptance**

The realization that you can be a caregiver is very powerful. You know you will do the very best job in caring for your loved one and though there will be many unfamiliar problems, you will find solutions. You know you are trying your hardest. This may be one of the most difficult jobs that you will ever have; it also may be one of the most satisfying.

## **Living and Grieving**

As you move through each day, you know that you must focus on your future. Although the past may be comfortable and at times comforting, you know that you must redirect your energies to the present and future. Grieving is a process that has no time limit. Each of us will grieve differently; some will start living fully with little prompting, some may work through this process slowly, while others may need professional help. Many of us have no others to be concerned about, while some of us may have family members - young or old who are dependent on what we do for them and what we say. Many look to us as their role model and will mimic how we are grieving.

The death of a loved one is often a transforming experience. In many cases it is an event which will prompt an introspective life review. It may redirect your understanding to what is truly important in your life. This internal review involves risk and the shedding of many layers of emotional comfort that have accumulated in your lifetime. It may require you to:

- take steps to learn something new,

- meet people outside of those you already know,
- get a job or to find a new one,
- continue your normal routine or
- allow you the freedom to listen to your passions and go after dreams.

When we challenge ourselves, we allow ourselves to grow and become stronger. Your steps may be small at first - you are beginning a new phase in your life. As with anything in life, you will have successes and failures. Be proud of yourself for each effort you are making. Your self-discovery and moving forward is important in the grieving process.

## **Finding Support**

Many individuals find comfort in support groups. Individuals that join support groups usually have something in common. The individuals can provide help and guidance to others in the group who may be going through a difficult period of coping with their loss. Support groups are also excellent sources for learning about new programs and services in the community. You may find that there are others in the group that may be having a more difficult time coping with their loss than you are. Many Bereavement and Grief support groups can be identified by a Social Worker, a Geriatric Care Manager, Physician, Parish Nurse, Nurse, Hospice program and Chaplain offices. Hospitals are a good source to call and ask for information about Bereavement and Grief support groups.

Others may rely on their families and friends to be their sounding board. What is important is that when you need help in any way, that you get it. It is okay to talk about how you feel. In fact, it is critical to express the different emotions that you are feeling. Let supportive friends and family help you at this time.

For many, their faith often helps them work through their emotions; it may give them the support and courage to make it through each day. Faith communities may bring to you the unconditional love and attention to help you through not only the emotional issues that you are facing, but also through the day-to-day responsibilities that you may have difficulty facing.

Some individuals go through the bereavement process without help from anyone. For some, privacy is soothing. For others being able to go about your routine without feeling like everyone is watching every move you are making is important. Getting

quickly back to your routine also can be very comforting. You will find out what works for you.

There are many books written on grief and bereavement. A few bereavement resources are listed below:

- *Letters to My Husband* by Fern Field Books
- *The Mourning Handbook* by H. Fitzgerald
- *A Handbook for Living as Someone Dies* by E. A. Johnson
- *On Death and Dying* by E. Kubler-Ross
- *How to Go on Living When Someone You Love Dies* by T.A. Rando

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Last Reviewed

Wednesday, March 20, 2024