
Introduction

Caregiving would be challenging enough if it were only about the tasks to be done and the appointments to be kept. In the real world, it is about so much more. It is about relationships and feelings, hopes and worries, dreams and disappointments.

When you are caring for someone with a life-limiting illness, your experience as a caregiver is colored by frequent changes and losses as the condition of the person you care for worsens. It is common to feel grief over these losses. It is also common to wonder about what the future will bring.

For many people, it is easier to talk about the tasks of caregiving than it is to talk about the difficult feelings that are part of experiencing illness and caregiving. Many caregivers wonder if they are alone in feeling sad, anxious, guilty and angry at times. In truth, such feelings are a normal part of caring for someone with a serious illness. Such feelings are a normal part of living with change, loss and grief.

Grief is not something that happens only after the death of a loved one. The grieving process may begin when you first suspect that something is not right and continue as you adjust to the changes that illness brings. Think of the many changes that are part of caregiving. Loss of freedom, loss of activity, changes in relationships, changes in responsibilities, new care tasks, and fears of what the future holds are just a few examples of the challenges.

Grieving is a normal reaction to loss – past losses, current losses and those that you anticipate may happen in the future.

Difficult Feelings

Some of the things people feel as they go through these changes are listed below. These feelings come and go. Experiencing more than one at a time is normal as you cope with the changes in your life. As you look through the list, circle the ones you are experiencing or have felt in the past.

- Feelings of guilt
- Feeling that life isn't fair
- Tearfulness
- Mood swings
- Anger
- Depression
- Feelings of emotional numbness
- Anxiety or feelings of fear
- Changes in sleeping and eating habits
- Poor concentration
- Forgetfulness or poor memory

- Loneliness
- Fatigue, exhaustion
- Feeling “keyed up” or restless
- Wanting this time to be over

Normal Reactions to Loss

The losses that you actually experience and your fears of other possible changes can trigger these feelings. It may help to know that these feelings may be related to:

- Loss of control
- Loss of social life, changes in relationships
- Loss of companionship
- Loss of the future that you had hoped for or dreamed of
- Loss of usual eating, sleep, work, and recreational habits
- Loss of independence
- Fear of losing your present family structure or routines
- Fear of starting over
- Fear of the unknown
- Fears related to life without your loved one

What You Can Do

There are steps you can take to help you cope with loss and work through your grief.

- Acknowledge that your losses and grief are real.
- Try not to judge yourself harshly for feeling angry or depressed.
- Be gentle in setting expectations of yourself and others.
- Talk to someone...a friend, family member, counselor or clergy.
- Get moving...yard work, a short walk or other exercise can release intense emotions and leave you feeling more in control.
- Make changes only as needed and put off major decisions when possible.
- Do the things you want to do now. Forget the chores that you can do later or ask someone to do some chores for you.
- Spend time with the people you love.
- Arrange for time for things you enjoy by asking for help from your family, friends, or a volunteer.
- Plan something simple and pleasant to look forward to...a phone call to a friend, a hot cup of coffee, a quiet bath, lunch date.
- Hang onto your sense of humor. Laughter can be a lifeline.
- Write about your feelings and thoughts in a journal.
- Nurture your spirit – read inspiring books, pray, meditate, spend time with others who share your beliefs.
- Talk with other people who are experiencing the challenges of illness and caregiving.

Find Out What Works For You

Sharing your feelings with others and asking for help can help you work through the difficult times and have more energy to do those things you want to do. You might have noticed that the person you care for is experiencing many of the same feelings. Understanding where these feelings come from can help you care for and support each other. Remember that everyone copes in different ways.

Your Hospice Care Team Can Help

We hope that you will see your hospice care team as a source of strength and guidance. It can be difficult to talk about such personal feelings. Please be assured that your hospice care team will respect your privacy.

References

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