



End-of-Life Caregiving


Caring Connections
a program of the National Hospice
and Palliative Care Organization



End-of-Life Caregiving

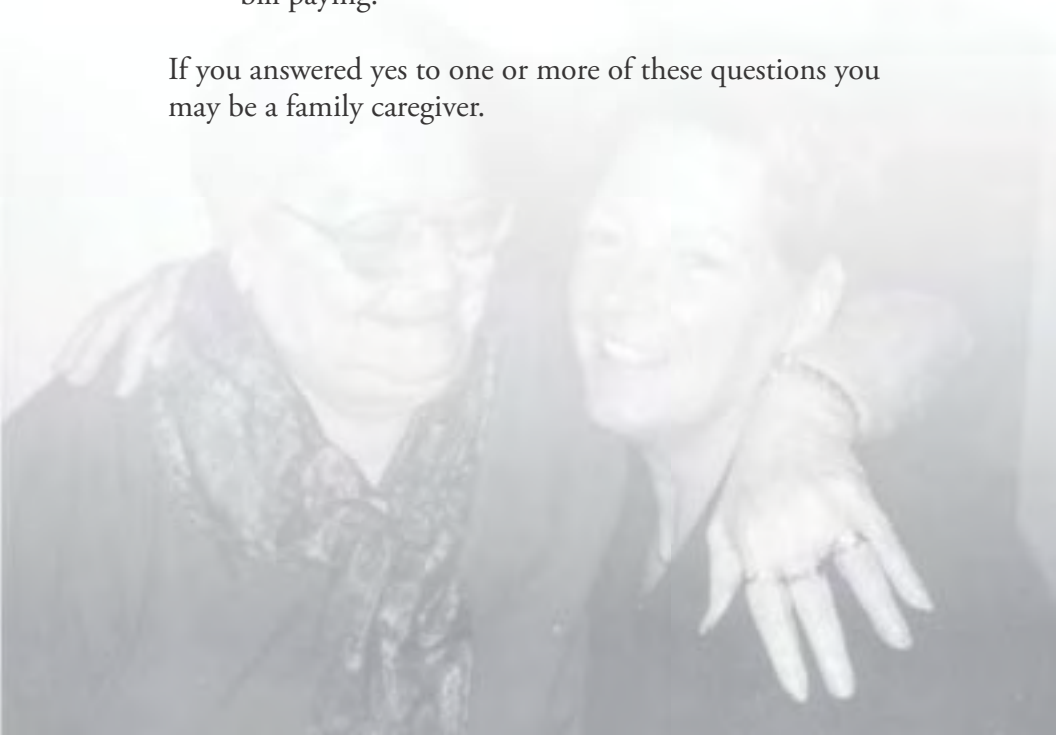
Are you a caregiver?

*You may not
consider yourself
a caregiver,
but . . .*

. . . do you regularly:

- Drive a family member, friend or neighbor to doctor's appointments?
- Make meals for someone?
- Help someone with household chores such as cleaning, grocery shopping, lawn care, etc?
- Make regular phone calls to someone to "check in" on them?
- Provide hands-on care, including bathing, help eating, toileting, or other help?
- Help someone make decisions about medical decisions?
- Assist someone with personal business affairs, such as bill paying?

If you answered yes to one or more of these questions you may be a family caregiver.



Caregivers provide support to someone who needs help. It doesn't matter how many hours per week are spent providing support. Caregivers may live with the person they are caring for, providing assistance with daily needs, or may visit the person weekly or call regularly. Being a caregiver involves an investment in time, energy and support.

What It Means To Be a Caregiver at the End of Life

Dying is a natural part of life, and may be filled with mixed emotions, and times of reflection for both the dying person and caregiver. There are losses for both the person who is dying and the person who is the caregiver. Caregivers often experience a variety of feelings, including:

- Loss—grieving the loss of the person who is sick, and feeling a sense of loss of your life before the illness.
- Acceptance of what is happening, including your role as a caregiver with new demands and duties.
- Letting go of hopes for a long-term future with the person who is sick, of life before being a caregiver.
- Finding purpose and meaning in the experience. Providing care for someone who is dying can be personally rewarding even in the midst of grieving losses and balancing the demands of caregiving.

Providing Care

As a caregiver you may need to provide for all aspects of your loved one's comfort. People who are near the end of life have complex needs so it is important to know various ways to provide support.

Physical Comfort

It will be very important for you to ask the person you are caring for if they are comfortable. The health care providers need to know if they are experiencing physical pain, breathing problems, confusion or other symptoms so that they can work to ease the distress. By talking with the person's physician and other healthcare providers, pain medication and other therapies can be provided to achieve a level of comfort.



- Ask your loved one if they are comfortable
- If they are experiencing pain ask them to describe the pain rate it on a scale of 0-10.
- Write down everything they say and review this before you call the physician and health care provider.
- If you have specific questions, write them down too.
- Write down the answers you receive so that you can refer to the information later.

Emotional and Spiritual Comfort

In addition to physical pain, your loved one may experience emotional and spiritual pain. They are experiencing many losses including the loss of control over their own life. It is important for you to continue to explain what is happening with your loved ones care, condition, and any other changes.



- Try and take time each day to talk to them about their feelings and to share your feelings with them.
- Be patient with yourself and the care recipient. Listen to what they want to share with you.
- Whatever feelings they have—let them know that they have a right to feel that way; do not try and talk them out of their feelings.
- Your loved one may wish to discuss their fears, concerns or distress with someone else, encourage them to do so. Offer to contact a friend, counselor or chaplain, and give your loved one privacy.
- Ask for help. The best way you can support someone else is to take care of yourself.

Care for Yourself

Caregiving can be a rewarding and exhausting experience. It is important that you manage the stress of being a caregiver by attending to your needs.



- Make a list of specific things that you need help with: grocery shopping, laundry, errands, lawn care, housecleaning, or spending time with the care recipient so you can do something else. When someone says “let me know if there is anything I can do” point to the list!
- Take a break from caregiving—even if it is 15 minutes a day that you do something just for you.
- Exercise and eat healthy.
- Subscribe to caregiving newsletters or Listservs for advice/ support when caregiving for a loved one.
- Attend a support group for caregivers.
- Pay attention to your needs and seek professional help to address grief, anxiety, or other issues. Many caregivers have times when they are lonely, anxious, guilty, angry, scared, frustrated, confused, lost and tired. If you feel like these feelings are overwhelming you, call your doctor, hospice or another community resource (see below) for help.

Being Prepared

Caregiving often comes with new responsibilities and unfamiliar tasks, yet most caregivers never receive training. The following information may help you with a current situation or prepare you for what may happen.

Decision Making

Has the person you are caring for told you their wishes for end-of-life care? In the event that you are asked to make or help make decisions it is important for you to talk about issues, including thoughts about potential life-prolonging treatments. Advance directives are tools that enable people to write down their preferences on a legal form and appoint someone to speak for them if they are no longer able. A living will, health care power of attorney, financial power of attorney, and plan for after care (funeral arrangements) can help ensure peace of mind for the ill person as well as you as the caregiver.



End-of-Life Care

Hospice is end-of-life care that involves a team-oriented approach to quality medical care, pain and symptom management, and emotional and spiritual support tailored to your loved ones needs. Hospice is available to anyone who has a life expectancy of six months or less. Hospice provides medical equipment and medications related to terminal illness. Support is given to you as the caregiver, including counselors to talk to, nurses and aides to teach you how to provide hands-on care, volunteers to help lighten your load and non-denominational chaplains to aide with any spiritual distress.



Community Resources

In addition to hospice, there may be other community resources that can help you and your loved one. Your Area Agency on Aging, Department of Human Services, and other organizations may offer services to ease your burden. These may include meals on wheels, caregiver training classes, transportation, friendly visitors and respite care so that you can have a break.



Preparing the Home

It is important to prepare the place where the ill person lives to ensure that they are safe and comfortable. Is there room for any special equipment that may be needed such as a walker, or commode? Are there special needs for the bathroom or bedroom needed to make living easier for the person?





Caregiving for someone at the end of life can be a challenging, but rewarding experience. Learning about the complex needs of the person you are caring for and the resources that can help will be important steps for you to take to prepare you for being a caregiver. Caregiving at the end of life may bring about many different feelings—it will be important for you to care for yourself and ask for help when you need it. ❁



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