

HOSPICE INFORMATION CENTER

for families, friends and professionals

funded by the Centers for Medicare & Medicaid Services

WHAT YOU NEED TO KNOW ABOUT CAREGIVING

- 1** *Who is a family caregiver?* A family caregiver is someone who provides essential unpaid assistance to a person with a chronic or life-threatening illness or a disability. Caregiving may include all kinds of care: day-to-day personal care, medical care, or managing financial and legal issues. There are almost 66 million family caregivers in the U.S. today. The majority of family caregivers are female; many are caring for both parents and children.
- 2** *Caregiving is a tough job.* Caregiving may affect our physical and emotional health; we often feel isolated, unappreciated, overwhelmed and exhausted. It is financially costly, especially if it interferes with our ability to work or requires extra expenses.
- 3** *Family caregiving affects families.* Relationships are strained by the pressure and time that caregiving requires. Spouses may feel resentful; children may feel neglected, or be confused about what they are experiencing. Parents and siblings may have disagreements on what their responsibilities are.
- 4** *Loss comes with caregiving.* If our family member or friend is ill, we may experience what is called “anticipatory grief.” Anticipatory grief doesn’t just mean that we anticipate grieving for somebody whom we know we are going to lose. It refers to dealing with all the losses we cope with along the way—the loss of independence, the loss of our plans together, the loss of our friends, the loss of our resources and lifestyle.

5 *Respite is important.* Taking time away from caregiving means that someone else will have to provide care while you aren't there. Sometimes we may need to take small steps, gradually trusting others to provide care in our absence. You may rely on family or friends, members of your faith community, or a hospice volunteer for respite care.

6 *Information can help.* Learn as much as you can about the condition of the person you are caring for. Try to stay organized. If you fall behind in the routine of life, give yourself a break; it happens. Always be sure to ask for help.

7 *Taking care of yourself is important too.* Stay healthy with diet and exercise. Find someone in an online group, or in a weekly support group, with whom you can honestly discuss your feelings, get advice and assistance, and talk about the frustrations and the joys that are part of the caregiving experience. Take care of yourself, even though it requires an effort.

8 *You are not alone.* Asking for help is a sign of strength, not a sign of weakness. Your feelings about the caregiving experience, whatever they are, are normal. Draw on your family, friends, faith community or other available resources. Professionals can help find support, assess what might be needed, and help us understand how caregiving is affecting our own health and well being.

9 *Hospice is an excellent resource for caregivers.* In many cases, the person we are caring for is ill or disabled; for many caregivers, part of the experience will include the death of that person. Advance care planning is an important part of that process; it includes asking what sort of care the person wants at the end of life and what is important to him or her as death nears. Hospices are an excellent community resource for caregivers and provide patients and caregivers with psychological, spiritual and practical support as well as respite care resources.

The caregiving experience is very difficult. We hope this factsheet helps you remember key points and resources that can help you.



For more information on hospice, grief and bereavement, or caregiving and end-of-life issues, please visit our website at www.hospicefoundation.org/hfacares or call us at: 800-854-3402.

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