

SALUTE to
Caregivers



What is Informal Caregiving?

As Americans age or face life with chronic illnesses and disabilities, many find themselves unable to fully care for themselves in their own homes but don't need full-time help.

Many want to stay in their own homes and retain the independence they have, or they can't afford an assisted living facility and are unable to find help from the government or insurance policies to help with costs.

To help those people stay in their own homes, millions of adults have taken on the role of informal caregivers for family members, friends, neighbors or members of their church community. According to the National Alliance for Caregiving, more than 34 million Americans have been a short- or long-term informal caregiver for an adult family member, neighbor or friend. The person receiving care may have a disability or illness, such as Alzheimer's or a physical ailment, or they may be elderly and unable to care for themselves. Another 9 million provide caregiving services for children with illnesses or disabilities.

These caregivers, who aren't paid for their work, provide a



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range of services to their loved ones. Some patients need significant care, so caregivers live with them, cook, clean, take them to doctor's appointments and whatever else the person needs to allow them to continue to live in their own homes.

Often, however, people need only occasional care or help with specific tasks, such as cooking, yardwork or driving, and relatives, friends and neighbors pitch in to help the person continue to live independently.

This informal caregiving

provides significant economic value. The AARP estimated the value of such services as \$470 billion in 2013, and that's continuing to increase. This exceeds the value of paid home care and total Medicaid spending in the same year, almost matching the value of

the sales of Wal-Mart, the world's largest company.

Caregiving offers many benefits, particularly for the person able to stay in their home, but caregivers face risks to their own physical and mental health and often face burnout.

Who are the Caregivers?

Caregivers and those receiving care cover a range of ages, genders and relationships, but, according to the Family Caregiver Alliance, older women are most likely to receive care, and women are by far the most likely to be caregivers.

Two-thirds of people receiving care are women, with an average age of almost 70 years old, but almost half of people between the ages of 18 and 45 years old receiving care are men. Women, in addition to being three-quarters of the informal caregivers, spend as much as 50 percent more time providing care than men.

Half of caregivers are caring for a parent or parent-in-law. Fifteen percent care for friend or neighbor; others, particularly older Americans who are acting as caregivers, are actually caring for their spouse, which sometimes puts people in the position of caretaking in poor health themselves.

Caregivers spend an average of 13 days each month doing tasks such as shopping, cooking or food preparation, housekeeping, laundry and administering medications; six days a month feeding, dressing, grooming, walking and helping with hygiene; and 13 hours a month doing research on their loved one's condition and how best to help, managing finances or coordinating with doctors.

Caregivers who provide complex care or spend more time providing care help with medical and nursing tasks and provide help with tasks such as getting



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in and out of bed and chairs. The average length of a caregiver's work is four years, with 15 percent of caregivers helping their patients for a decade or more. Family caregivers say they spend more than 24 hours a week on caregiving, many on top of full-time jobs. (The average caregiver in the U.S. is in her late 40s.) Those who live with the care

recipient spend more time on caregiving tasks than those who don't.

Caregivers also report having decision-making authority or power of attorney over such things as treatment, communicating with doctors and other health care providers and advocating on the recipient's behalf with health care professionals, community organi-

zations, insurance companies and government agencies.

Informal caregivers, many of whom do not have special skills suited to these tasks, do so because they feel a personal responsibility for their loved ones. Almost half say no one else can do it or insurance will not pay for home care.

Self Care for Caregivers

Spending a significant amount of time and energy caring for another adult can be difficult, even causing harm to the caregiver. According to the American Academy of Family Physicians, caregiving can lead to stress, feelings of being overwhelmed, allowing one's own health or needs to suffer and physical strain, if the caregiving requires physical exertion.

WHAT ARE THE RISKS?

Caregivers are at an increased risk of anxiety and related disorders; diabetes; cardiovascular diseases such as high blood pressure and cholesterol and a greater risk of a heart attack; heartburn; infection; obesity; pain; and depression. You also should watch out for a tendency toward alcohol, tobacco or drug abuse; caregivers are at a greater risk of substance abuse as a way to cope with their own problems.

MAKE YOUR HEALTH A PRIORITY

Caregivers can take a number of small steps to ensure they're staying healthy, both physically and emotionally. Eat a balanced diet and get enough rest (this means sleep, but also includes resting throughout your work if you provide physical care). Exercise 30-60 minutes at least four days a week, maybe taking your loved one on a walk with you if you can or trying water aerobics or some other exercise. Find ways to control your stress, such as yoga, meditation, journaling, seeing a counselor or spending time on a hobby.

GO TO YOUR DOCTOR

Make sure you're getting regular checkups and getting the appropriate health care, including preventative screen-

ings for cancer, heart disease and diabetes. Keep up to date on vaccinations; this is especially important if your loved one's immunity is compromised and can't get vaccinations themselves. You also can

talk to your doctor if you are experiencing signs of depression and anxiety and ask for a mental health evaluation.

TAKE A BREAK

Don't feel guilty about tak-

ing time away from your charge. When you're feeling overwhelmed or unable to fulfill your tasks, ask other people for help. Look at the schedule and see what changes can be made to require less

work of you or tasks with which other people can help. Be honest with yourself about how much time you're able to give and what tasks you can complete and still meet your own needs.



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Respite Care

Respite care is available as a support for informal caregivers — to give them time off, fulfill needs they are unable to meet and otherwise help take care of people who need significant care.

According to the U.S. Department of Health and Human Services, the available options for respite care vary; caregivers and their patients can determine what's available in their community and mix and match the different services to meet their needs. Visit eldercare.acl.gov for more information or contact your area agency on aging to learn what options you have.

ADULT DAY CARE

Many caregivers are still working full-time while also providing care to a parent, spouse or other relative and need help during the workday. Adult day care provides companionship and assistance during the day. It also is available for caregivers who aren't working but need to run errands, go to doctor's appointments or take care of other needs during the day. Assisted living communities may provide some activities that are available to others in the community.

IN-HOME RESPITE CARE

This type of care could include companion services to help with supervision, entertainment and companionship; homemaker ser-

vices to assist with housekeeping, cooking or shopping; personal care services to help the person bathe, get dressed or go to the bathroom; and skilled care services, such as providing health care or administering medications.

VOLUNTEER RESPITE CARE

You are an informal caregiver; when you need help, look for others who can provide the same type of informal care. Other family members, neighbors, friends and even volunteers from the community may be able and willing to pitch in as needed, helping with different tasks and giving you time for yourself.

PAYING FOR RESPITE CARE

Some of these services, such as community volunteer, interfaith programs or Meals on Wheels, shouldn't cost you anything. Many programs are subsidized by the government or by nonprofits, depending on the type of agency and the specific services needed. Some people have long-term care insurance policies that will help pay for these costs, as well. This is another question to ask the area agency on aging, which can point you to financial assistance.



Finding Quality Respite Care

Caregivers want to know their loved ones are taken care of when they're not able to be with them. If you're hiring a professional part-time caregiver, either to give yourself a break or to meet needs that you're unable to meet, or using adult day care or other programs, you want to make sure your loved one will be in good hands.

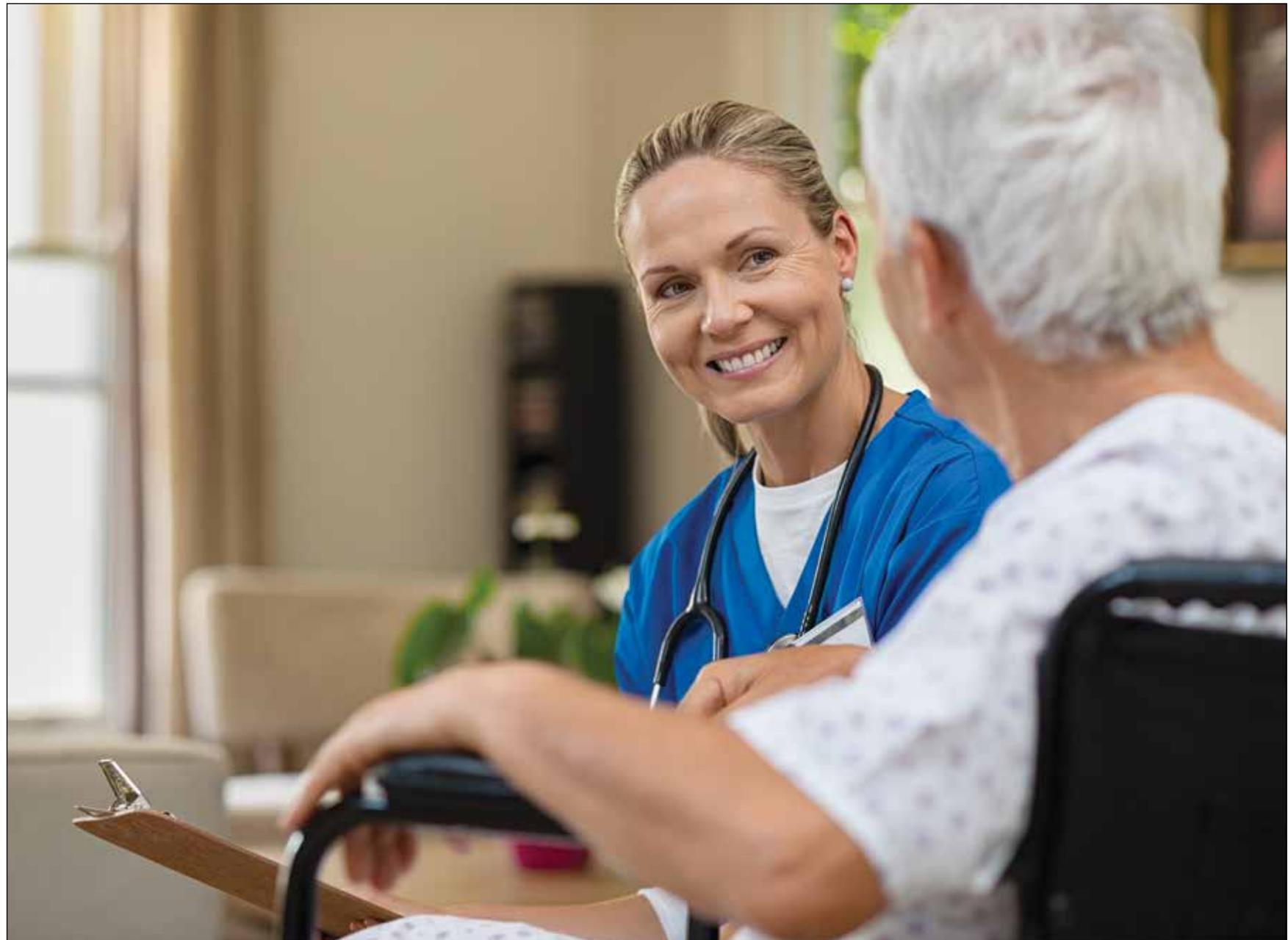
The U.S. Department of Health and Human Services' Elder Care program offers a number of questions to ask respite care managers as you're researching resources.

WHAT TO ASK

- How many people will the respite care manager take care of at any given time?
- Can family members interview the respite care provider?
- Does the program provide transportation, either for the caregiver or the patient?
- What is the screening process for caregivers? How are the caregivers trained, supervised and evaluated?
- How do the caregivers handle emergencies with the patient or unexpected situations?
- What are the fees associated with the service, and what will the respite care provider do in exchange for those fees?

You also should interview providers. They should be insured, and always ask for references, as well. Follow up on those references. Try to talk to people whose loved ones are in a similar circumstance to your family so you can find a provider who's a good fit for your situation. Other questions to ask include:

- Have you ever worked with someone in the same medical condition as my relative?
- What is your background and training?
- What is your availability? If you're not available, do you have a back-up?
- What is your history with respite



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care?
Ask how they would handle certain situations and why they left previous jobs. It's a job interview; treat it that way.

RESOURCES

As you're looking for respite care,

contact your area agency on aging, or look for other resources. The Alzheimer's Association (www.alz.org) provides support for people diagnosed with Alzheimer's and their caregivers; the Family Caregiver Alliance (www.caregiver.org) has a resource center and

a newsletter for caregivers; the National Alliance for Caregiving (www.caregiving.org) is a collaboration between private and government agencies; and the National Adult Day Services Association (www.nadsa.org) offers information on adult day care.

National Support Program

The federally funded National Family Caregiver Support Program provides grants to states that pay for a variety of different support systems for people who are caring for family members, with the intention of avoiding caregiver burnout and helping older Americans stay in their homes as long as possible.

This is good not only for the adults, who remain part of their social circle, but it also tends to cost less than putting people in group homes.

According to the Administration for Community Living, the services include counseling, organizing support groups, caregiver training, respite care and supplemental services, as well as helping people access these and other services available through government programs and nonprofit organizations.

These are not intended to be a full suite of services or provide full-time care, but can give caregivers a break or help fill specific needs. Studies have shown that such services help reduce depression, anxiety and stress among caregivers, as well as helping them provide care longer.

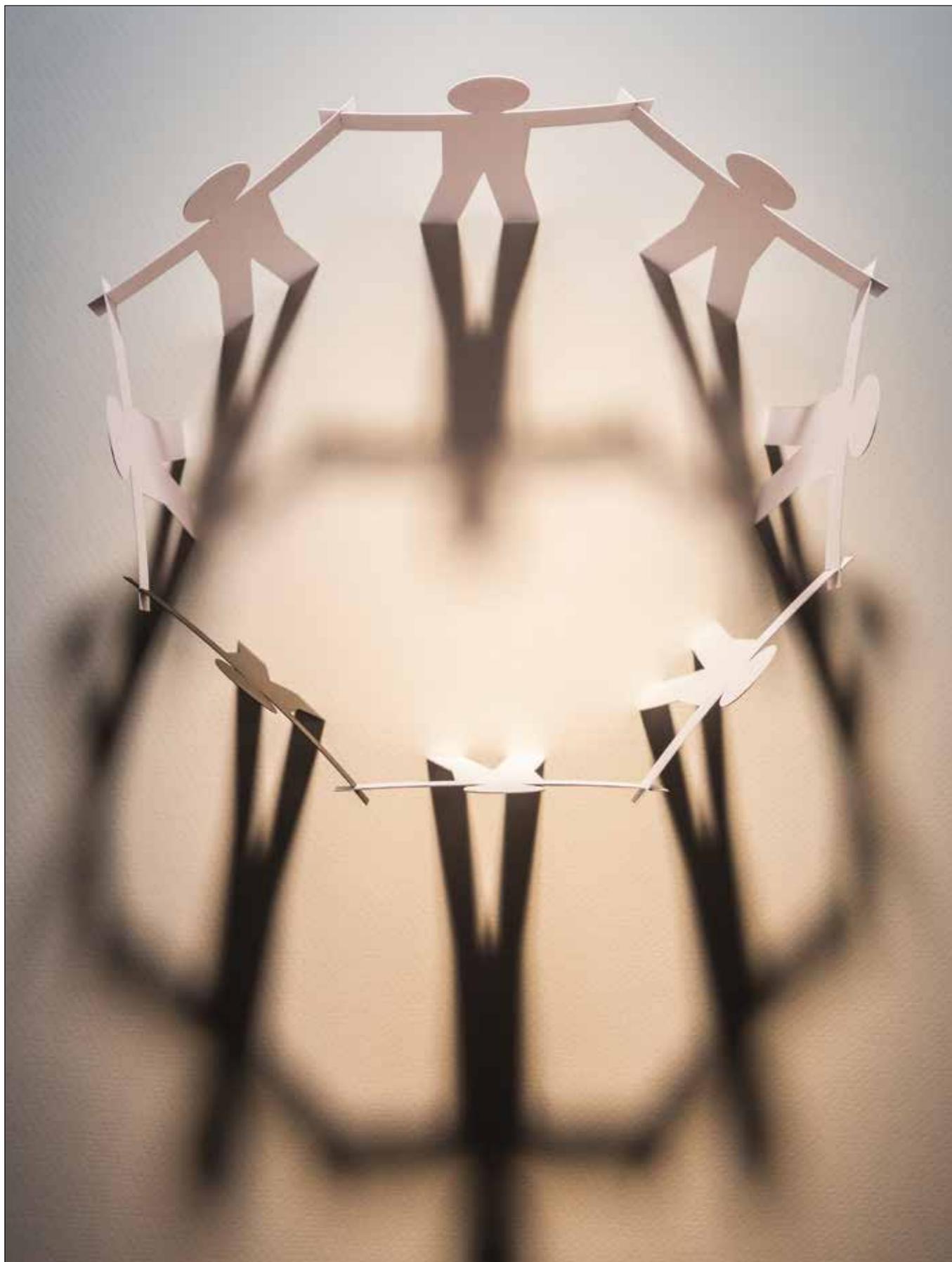
Eligible caregivers include adult family members or other informal caregivers who provide care to individuals who are 60 years of age and older or who are providing care to people of any age with Alzheimer's disease or other neurological disorders.

Services also are available to people who are 55 years or older and raising children who aren't theirs or who are providing care to adults with disabilities.

According to the ACL, about 700,000 caregivers received services in 2014, including more than 1.3 million contacts with caregivers to help connect them with services; peer support groups, counseling and training for more than 100,000 caregivers to help them cope with the stresses they're feeling; and respite care of almost 6 million hours for more than 600,000 caregivers, offering relief from their caregiving responsibilities and allowing the caregivers time to take care of themselves.

Almost three-fourths of caregivers who used the program said these services allowed them to provide care at home for longer than they could have otherwise.

The services offered are different in each state, and not every caregiver will be eligible for all of the programs. Check with your state to see what specific services are available.



Hospice Care

Many people are unclear on what hospice care includes. According to the National Hospice and Palliative Care Organization, this is high-quality care for “people facing a life-limiting illness or injury” that brings a team of health care providers to handle a patient’s medical care, pain management and emotional support, including support for the family and caregivers of the patient.

It is not solely for people who are dying; people can get into hospice care for a time to handle a difficult health situation but leave hospice care when it is no longer necessary. According to the NHPCO, close to 7 percent of patients in 2016 left hospice care because they were no longer terminally ill, while another 6 percent left on their own.

In 2016, 1.43 million Medicare beneficiaries used hospice care, with 101 million days of care paid for by Medicaid.

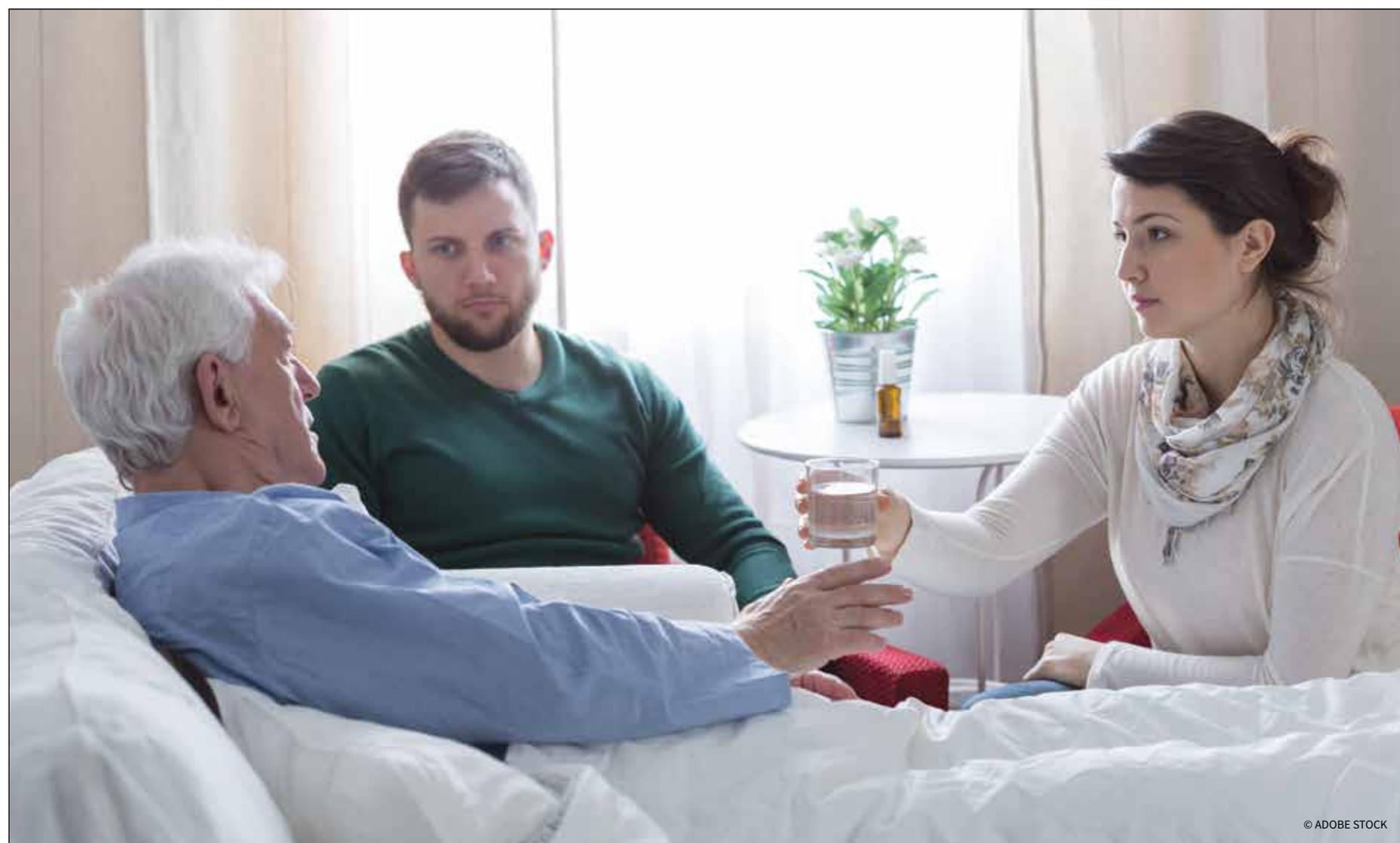
Based on your loved one’s disease and condition, consider calling a local hospice provider and determining whether they can help with your relative’s care.

SERVICES AVAILABLE THROUGH HOSPICE

Hospice care providers help manage the care recipient’s pain and symptoms; provide medications, medical supplies and equipment; coaches the family on how to care for their loved one; offers short-term inpatient care as needed; and provides assistance with the emotional aspects of dying, including bereavement care for family members.

WHO’S ON THE TEAM

Hospice care providers



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work with the caregiver, the patient and the family to create a plan that meets the care recipient’s needs and desires. The team includes the recipient’s doctor, a hospice physician, nurses, home health aides, social workers, clergy members, volunteers and speech, physical or occupa-

tional therapists, as needed. The recipient and family members are part of the discussion and planning, as well.

CHOOSING A PROVIDER

Most insurance plans, including Medicare and Medicaid, cover hospice, but you should check with your

provider to see if there are specific providers. From there, talk to your loved one’s doctor. Look for services close to you; hospice care is often provided in a private home, which allows your loved one to continue living at home or with family members instead of a facility.

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