

Caregiving: Providing informal care to a friend or family member



Who are informal caregivers?

A 2020 report by AARP found that more than 50 million adults in the U.S. have provided care to an adult or child sometime within the past year. Unpaid, or informal, caregivers are a main provider of long-term care for adults living at home and in the community.¹ The prevalence of unpaid caregiving is increasing as people live longer with more chronic conditions; since 2015, there are approximately eight million more adults providing care to another adult. Almost 90% of these caregivers provide care for a relative – over half providing care to a parent/parent-in-law, 11% to a spouse or partner, 10% to a grandparent or grandparent-in-law, and one percent to an adult child. Another 11% are caregivers to a friend or neighbor.²

What type of care do caregivers provide?

Caregivers provide approximately 24 hours of care each week and most help with Instrumental Activities of Daily Living (IADLs). Caregivers also help with Activities of Daily Living (ADLs) and with medical or nursing tasks.¹ ADLs are skills required to manage basic physical needs such as personal hygiene and grooming, dressing, toileting, walking independently and eating. IADLs include more complex skills that help people live independently in the community such as managing finances and medications, meal preparation including shopping for food, housekeeping, laundry, transportation, and communicating with others.¹

How do you know if someone needs caregiving?

According to AARP, the following are signs indicating that a person might need caregiving support:

- A lack of mobility
- Symptoms of depression and/or dementia
- Piles of unopened mail and unpaid bills, uncashed checks, unusual financial transactions or larger than usual amounts of money being donated to charities
- Car accidents (even just dings to the car), close calls, tickets, getting lost driving to familiar places, or not remembering how they got somewhere
- Changes in appearance or hygiene
- Not keeping up with chores, eating habits or hobbies
- Taking medications incorrectly or not at all

If you see any of these signs, you can get a more comprehensive assessment from your friend or family member's primary care physician, who is the most familiar with their medical history.

Informal or Paid In-Home Caregiver – How to decide?

Being an informal caregiver for a friend or family member can be a rewarding experience. However, sometimes if there is a higher level of care needed or if the care is too time consuming or stressful for the caregiver, it can be an overwhelming responsibility.⁴ Many caregivers feel that caregiving has given them a sense of purpose or meaning, but also feel the impact of providing care on their time, financial and personal well-being, health, family relationships, and their work.¹

Another option is to hire a private caregiver. Johns Hopkins Medicine lists some [questions](#) to ask yourself if you are considering using a private caregiver. The page also includes suggestions for how to find appropriate care for your care recipient so that their needs and desires will be considered.

AARP has a [webpage](#) that provides more information on finding the right paid home care worker and describes the types of workers that can help with caregiving:

Types of paid In-home caregivers:

Personal care aides (PCAs) are not licensed and can vary in their levels of training and experience. Some states do not have formal training requirements or standards. They can help with bathing and dressing, light housekeeping, preparing meals, and providing transportation and companionship. Medicare and private health insurance typically do not cover the cost of hiring a PCA.

Home health aides (HHAs) are available to monitor the patient's condition by checking vital signs. They can help with ADLs, and can also provide companionship, light housekeeping and prepare meals. They are required federally to have obtained 75 hours of training, but other training and certification requirements vary by the state in which you live.

Licensed nursing assistants (LNAs) and certified nursing assistants (CNAs) can perform medical-related tasks such as taking vital signs, setting up medical equipment, changing dressings, cleaning catheters, monitoring infections, conducting exercises, walking assistance, and administering some treatments. These are directed by a registered nurse or a nurse practitioner. They can also help with bathing, toileting, feeding, changing bed linens, and serving meals. They are also required federally to have obtained 75 hours of training.

Skilled nursing providers (licensed practical nurses (LPNs)) are licensed by states to provide medical care such as administering IV drugs and tube feedings, giving vaccines, changing dressings, and providing diabetes care and education to caregivers and patients. Some specialize in occupational therapy, physical therapy, or speech therapy. Medicare covers home health skilled nursing care in certain situations.

Registered nurses have met all licensing requirements mandated by their state's nursing board and can also provide direct medical home care.

Research Spotlight: Caregiving for those with Chronic Disease at End-of-Life

The following findings are from Karla Washington, PhD, MSW and other researchers on the needs of caregivers for older adults with chronic conditions who are at the end of life.

Digital social support and technical assistance can help caregivers. Findings from research indicate that caregivers can receive beneficial social support over video conferencing software.¹ This was especially useful during the pandemic, when gathering in-person can put those with chronic conditions at increased risk for infection. Additionally, it was found that videos were a useful tool for educating caregivers.² Online social support and technical assistance offer promising avenues for providing educational or social support to caregivers who cannot gather in-person.

Caregivers share a range of support needs and challenges. Research has shown that families of care recipients have a need for informal and formal support, self-care help, feeling self-assured in their caregiving abilities, ability to derive meaning, and the need for resources.³ Caregivers report feelings such as low quality of life, anxiety, and depressive symptoms across racial and socioeconomic categories.⁴ This research reveals that caregivers have many similar needs despite differences, and they need the support of outside help to provide the best care possible.

What can help caregivers provide the best care?

Care planning: According to the CDC, a care plan reviews the health conditions, care needs, and treatments of the person receiving care and outlines how to manage the care so that you can provide the best care. If you are a caregiver, you can work with your care recipient and their medical team to develop a care plan.

Medical support: Doctors and care managers can help caregivers by providing them with educational resources about their care recipient's condition and care needs. Working with the care recipient's health team can improve the communication between you and health professionals and increase the quality of your care.

Completion of all legal documents and financial help:

In addition to a care plan, there are other activities that are important to protecting both the caregiver and the person receiving the care. Information on these can be found [here](#) and include organizing important papers, educating yourself about the recipient's insurance and exploring other financial help, and links to get legal advice. The [ARCH National Respite Network](#) lists resources to help identify financial assistance for family caregivers, such as Medicaid, Veterans services, etc., helpful articles, information on respite and other supports and services.

Online resources: Caregivers can access helpful resources online that provide information about essential caregiving responsibilities. The National Institute on Aging has a [webpage](#) with frequently asked questions about caregiving, tips to getting started being a caregiver, suggestions on how to speak to your friend or family member's physician, finding resources in your area, and other helpful information.

What if you are unable to keep caregiving?

There are many reasons why caregivers of friends and family might need to stop providing care – due to situations that arise in the caregiver's life or if the recipient of the care requires a higher level of nursing care. Deciding to stop caregiving is hard and often caregivers avoid the subject until something forces the change. It frequently causes caregivers to feel guilty that they are not living up to the promise of being able to provide care to their friend or loved one. The AARP discusses some [ideas](#) on how caregivers can approach, and live with, the decision to stop caregiving while assuring that their own and their friend's or loved one's best interests are considered.

How can caregivers take care of themselves?

The challenges of caregiving can be alleviated by help and support in many different forms. Caregivers can access resources and quality information to help them balance caregiving with their own life responsibilities and decrease their care burden and stress. The following are areas of support that are important:

Emotional and Social Support: Caregiving can be stressful and exhausting; and caregivers need to be aware if they need help. You can reduce caregiver stress by giving yourself a break, simplifying communication, using on-line resources, joining a support group, taking time to talk to close friends or family members, and taking care of your own health. [AARP](#) discusses how to make caregiving less overwhelming and lists links to resources.

Respite Care: Another important piece of caregiver support is respite care, which is when someone takes over for the caregiver for a set amount of time. This can provide caregivers with needed rest and can prevent caregiver anxiety and health problems. Help can come from family, friends, volunteer groups, religious organizations, government agencies, or people who are paid to provide respite. Respite care can be provided in the care recipient's home, or at a facility such as an adult day care center. [AARP](#) tells you how to create a plan for respite care.

Geriatric Care Managers: These care managers are usually licensed nurses or social workers trained in caring for older people and can be advocates and guides for overwhelmed family caregivers. Neither Medicare nor Medicaid pay for geriatric care management services. Long-term care insurance may cover some of the costs and some employee assistance programs cover some geriatric care management fees so that caregivers miss less work time. For more information on geriatric care managers and to find one, go [here](#).



Resources

General Caregiving:

Family Caregiver Alliance has a website that provides tips, resources, and information for caregivers. They offer self-care advice, tips on care activities, and links to resources for your state.

Website: <https://www.caregiver.org/>
 Services by State: <https://www.caregiver.org/connecting-caregivers/services-by-state/>

AARP Family Caregiver webpage offers resources and information on caregiving. They also offer more specialized resources for people that need help locally.

Website: <https://www.aarp.org/caregiving/>

Alzheimer's Association offers tips for caregivers of those with Alzheimer's disease and related dementias. You can find a chapter in your area that might offer local support.

Website: <https://www.alz.org/help-support/caregiving>

National Alliance of Caregivers is a non-profit coalition of national organizations that build partnerships within research, advocacy, and innovation to make life better for family caregivers.

Website: <https://www.caregiving.org/resources/>

Accessing Supplies:

Eldercare Locator, a service of the U.S. Administration on Aging links people to state and local Area Agencies on Aging and community-based organizations that serve older adults and their caregivers. Here you can find an Area Agency on Aging in your area, which offers respite care, meals on wheels, and help accessing medical supplies.

Website: <https://eldercare.acl.gov/Public/index.aspx>

Respite Care Links:

The Alzheimer's Association offers information and advice on respite care when you're caring for a patient with dementia.

The Department of Veterans Affairs provides up to 30 days of respite care per calendar year for people caring for former service members.

The National Adult Day Services Association has consumer information on adult day care services and a tool to find centers in your area.



Financial Resources:

US Government Services and Information website has information on how you can get financial help for caregiving from organizations, Medicare, or Medicaid in your state.

Website: <https://www.usa.gov/disability-caregiver>

AARP's caregiver website offers financial and legal advice for building a care plan and getting financial support as a caregiver.

Website: <https://www.aarp.org/caregiving/financial-legal/>

Social Security's Extra Help Program helps with prescription drug costs, premiums, and co-payments associated with Medicare costs. You can find out if you qualify on the website.

Website: <https://www.ssa.gov/benefits/medicare/prescriptionhelp.html>

Self-Directed Services are offered by Medicaid, which allows a Medicaid recipient to pay for care from a family member or chosen caregiver in their own home.

Website: <https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html>

You can research the regulations in your own state to figure out how to qualify for Self-Directed Services payments. Different states might also provide tax credit programs for caregivers. For instance, Missouri provides a Shared Tax Credit Program for caregivers of older adults ages 60 and over. [Learn more about the Missouri Shared Tax Credit here.](#)

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Research Spotlight

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