

ISSUE BRIEF

**THE IMPORTANCE OF CAREGIVER
SUPPORT FOR THE HEALTH AND
WELL-BEING OF OLDER ADULTS**



Executive summary

Health access and quality are key aspects of social determinants of health, and the ability of older adults and their families to access caregiver support is an important element of overall access to care. Caregiving is the provision of temporary or ongoing assistance to support everyday tasks and/or health needs. Access to these supports has many favorable impacts for older adults. These include maintenance of dignity and independence, as well as reduced risk of hospital and nursing home admission.

Home health and home care are the two main types of paid, professional caregiver support, and these services are often supplemented by informal caregiving that is provided by family members, friends, or neighbors. Medicare covers certain types of in-home care, but these services are limited, and eligibility is tied to special circumstances. Despite Medicare coverage of some home health services, these services can be hard to access because families are unaware of the benefits, and they are sometimes provided with incorrect or misleading information about their eligibility and entitlements.

Over time, changes in federal policies have greatly reduced the amount of in-home care that Medicare beneficiaries receive. Reductions in Medicare coverage for paid caregiver support have placed added burdens on informal caregivers, whose caregiving roles are often physically and emotionally demanding. In response to the many challenges facing informal caregivers, numerous organizations offer resources and information, including strategies to help caregivers be as successful as possible in their critical roles.



Introduction

Factors such as income, walkable neighborhoods, and educational attainment are examples of social determinants of health, characteristics of the environments in which people are born, live, work, play, and worship that affect an array of health risk factors and outcomes.¹ Social determinants of health are frequently grouped into five categories:

- Economic stability
- Education access and quality
- Healthcare access and quality
- Neighborhood and the built environment
- Social and community context

These factors can impact the health of older adults through their influence on an array of issues ranging from health literacy to the distance to the nearest pharmacy.^{2,3,4,5} This issue brief focuses on the support that caregivers provide to older adults—a key element of health access and quality—and how caregiving impacts seniors as well as caregivers themselves.

Caregiving is critically important for older adults

Caregiving is the provision of temporary or ongoing assistance to support everyday tasks and/or health needs. Older adults who receive caregiver support can live in an array of community-based residential settings or in institutions. For older adults who live in the community and wish to remain independent in their own homes, access to caregiver support reduces the risk of nursing home admission, with one study showing a 60 percent reduction in risk among adults aged 70 and older who have access to these important services.^{6,7}

Home health care and home care are different types of support

Home health care involves clinical or medical services such as physical and occupational therapy, administration of prescription medications, medical tests, monitoring of health status and wound care. Home health care is typically used by older adults who have significant medical concerns, those who have had a recent injury, who are at high risk of falling, and people with serious health conditions. Examples of older adults who may use home health services include:

- Those who have been recently discharged from a hospital, rehabilitation facility, or a nursing home
- People who need to be monitored following a change in their medication regimen
- Older adults with health challenges that prevent them from safely traveling to a doctor's office
- Seniors with functional decline who may regain independence with mitigated by occupational or physical therapy.

By contrast, home care consists of non-medical services for people who need assistance with daily activities and other tasks that help them remain independent in the community. Home care services may include help with bathing, dressing, and grooming, transportation to appointments, meal preparation, cleaning, financial management, and companionship such as reading aloud. Older adults who may benefit from home care include:

- People who need help with basic activities of daily living like bathing and dressing
- Seniors who are active but no longer drive and need assistance with transportation
- Older adults who need or want support with household responsibilities like cooking, cleaning, and shopping
- Seniors who are lonely or isolated and would benefit from companionship.

Home health care and home care support can be provided for a short time following an acute health event, or over longer periods to meet the needs of ongoing health or other challenges.

Many types of health professionals provide caregiver support

Caregivers are often categorized into two groups: formal and informal.

Formal caregivers are paid for their work, and they have a wide range of training, skills, and responsibilities. For example, people with a high school diploma can work as home care aides, although in some states they must also be certified. By contrast, home health nurses frequently have a bachelor of science in nursing and have worked as a registered nurse for at least two years.

Intermediate between home care aides and home health nurses are other formal caregiving roles, such as certified nursing assistants and licensed practical nurses. The tasks that formal caregivers perform are based on their training and credentials. While home care aides may run errands, clean the home, prepare meals, and assist with personal care, home health nurses assess patients' health needs, develop care plans with a physician, monitor and evaluate response to treatment, administer medication, take vital signs, and coordinate care with other healthcare providers.

Formal caregivers: People who are paid for their services and who have training and education in providing care.

Informal caregivers: People who care for family, friends, or neighbors, often without payment.

The second caregiver category includes people who provide informal care. Informal caregivers are not paid for their work in large part because the care they provide is linked to a personal relationship they have with the care recipient. Examples of informal caregivers who support older adults include their spouses, adult children, siblings, friends, and neighbors. About 44 million Americans provide care for family members, and these informal caregivers provide an average of 24 hours of care each week.⁸ In most cases, informal caregivers have no specific training or resources that support their complex role. And yet, depending on their physical abilities, these caregivers frequently perform the same tasks as home care aides, along with higher level tasks such as managing and administering medication and helping to coordinate care. Unlike formal caregivers, informal caregivers who reside with the care recipient rarely have a “day off.”

Medicare covers some types of caregiver support, but eligibility criteria apply

Medicare coverage for in-home care is limited and provided under special circumstances.⁹

Coverage includes:

- Part-time or intermittent skilled nursing care
- Physical therapy
- Occupational therapy
- Speech-language pathology services
- Medical social services
- Part-time or intermittent home health aide (home care) services
- Injectable osteoporosis drugs for women

Under Original Medicare, there are specific eligibility requirements for these in-home services.

The care recipient must:

- Have Medicare Part A and/or Part B
- Be under the care of a doctor and receiving services under a plan of care created and reviewed regularly by a doctor
- Be certified by a doctor as needing one or more of the following:
 - Intermittent skilled nursing care (other than drawing blood)
 - Physical therapy, speech-language pathology, or continued occupational therapy services
- Be certified by a doctor as homebound
- Receive therapy from a home health agency that is approved by Medicare
- Be expected to improve in a reasonable and generally predictable period of time

Part-time or intermittent skilled nursing care is needed for fewer than seven days each week or fewer than eight hours each day, typically over a period of no more than 21 days.

People are not eligible for in-home care benefits if they need more than part-time or intermittent skilled nursing or if they are able to leave home for medical treatment or short absences like attending religious services.

Older adults face significant barriers in accessing formal caregiving services

The Center for Medicare Advocacy has summarized several barriers to accessing Medicare benefits for in-home care.¹⁰

- Many beneficiaries and their families believe Medicare's in-home health benefits cover care for only a short time, and they are unaware that these benefits are unlimited if the care recipient meets qualifying criteria.
- Beneficiaries and their families may be provided with incorrect or misleading information about in-home care eligibility requirements and the services to which they are entitled under the home health benefit.
- Although Medicare authorizes 28 to 35 hours per week of home health aide support, many beneficiaries are unable to access this level of care.
- Over time and in response to changes in federal policies, the amount of in-home care that is delivered to Medicare beneficiaries has decreased substantially.

Average number of visits beneficiaries received¹¹

1998



14.1 Skilled nursing visits



13.4 Home health aide visits

2017



8.4 Skilled nursing visits



1.6 Home health aide visits

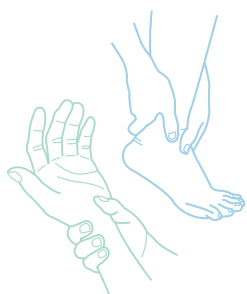
The collective impact of access barriers to in-home care are reflected in findings from a study showing that only 11 percent of homebound seniors received any in-home care between 2011 and 2017.¹² When older adults and their families are unable to access formal caregiving support, the burden often falls to informal caregivers.

Informal caregivers face many challenges

Many informal caregivers provide dedicated support for loved ones, and their caregiving roles offer a sense of fulfillment, and satisfaction with feeling needed and useful.¹³ However, informal caregiving is also physically and emotionally demanding. Demands on these caregivers have increased over time in response to the aging of the U.S. population and difficulties associated with securing adequate in-home care. A report by AARP and the National Alliance for Caregiving highlighted trends that point to substantial increases in the burden of informal caregiving in the United States.¹⁴ The table below shows changes in several characteristics of unpaid care that have occurred between 2015 and 2020:

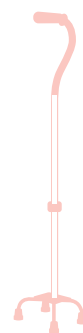
	2015	2020
Number of Americans providing unpaid care	43.5 million	53 million
Percent of Americans caring for more than one person	18%	24%
Percent of caregivers who have difficulty coordinating care	19%	26%
Percent of Americans caring for someone with Alzheimer's disease or dementia	22%	26%
Percent of family caregivers reporting their own health as "fair" or "poor"	17%	21%

The AARP/National Alliance for Caregiving study showed that 61 percent of family caregivers were also employed while providing care, and 45 percent reported that caregiving has resulted in an unfavorable financial impact.¹⁴ The Centers for Disease Control and Prevention (CDC) recognizes the public health challenges and impact of informal caregiving. CDC research has shown caregivers reporting poor mental health and poor physical health. About 37 percent of caregivers reported insufficient sleep, and many are also managing their own health conditions.



40.7%

of caregivers report having
2 or more chronic conditions



33%

report having
a disability

Because the need for informal caregivers is expected to increase in the future, families and other stakeholders must plan strategically to ensure that these caregivers are equipped with the resources they need to be successful in their critical role. The CDC views family caregiving as a public health issue, and offers several recommendations to address these challenges:¹⁵

Educate the public about the importance of caregiving and the resources and supports available to them before they begin.

Educate healthcare providers to be mindful of the health risks for caregivers, encourage caregivers' use of available information and tools, and make referrals to supportive programs and services.

Increase awareness of and access to evidence-based programs and services that can help caregivers and care recipients and increase access to these programs and services.

Encourage caregivers to get regular check-ups, use preventive services and engage in self-care to maintain health.



Where to go for help

Recognizing the challenges that informal caregivers face, many organizations offer information and resources to support these individuals. Some of these organizations include:

The [National Family Caregiver Support Program](#) (NFCSP) provides grants to states and territories to fund various supports that help family and informal caregivers care for older adults in their homes for as long as possible. Grant examples include individual counseling, support groups organization, caregiver training, and respite care.

The Administration for Community Living offers a [free eldercare locator](#) that helps people who need assistance with state and local area agencies on aging and community-based organizations that help older adults.

[Next Step in Care](#) provides information and resources for family caregivers as they assist loved ones in making transitions between various care settings.

The [National Alliance for Caregiving](#), the [Family Caregiver Alliance](#), and the [Caregiver Action Network](#) offer information and resources to support informal caregivers, and the National Alliance for Caregiving has also identified six steps to guide state-level caregiving plans as well as five policy recommendations to improve support, training, and education for informal caregivers.^{16,17}



Conclusion

Social determinants of health include factors that facilitate or inhibit the ability of older adults to access high quality, caregiver support, either provided by paid professionals or informally by family members, friends, or neighbors. Historically, Medicare has covered certain types of in-home care, but these services are limited, and coverage for them has decreased over time. Compounding the reduced coverage are other barriers that inhibit access to formal services, including lack of consumer knowledge about eligibility and entitlements for in-home support, misinformation from providers, and challenges accessing complete benefits once in-home care is initiated.

Difficulties associated with accessing formal caregiving are compounded by a parallel set of challenges facing informal caregivers. These dedicated family members, friends, and neighbors frequently provide dozens of hours of unpaid caregiving each week, and this support is often what allows care recipients to continue residing in community settings. The burden of informal caregiving is well-recognized, and many organizations have stepped forward to provide information and resources to this important segment of the health care labor force. Policies that encourage support of informal and formal caregiving will help older adults remain independent in the community, a much preferred and less expensive alternative to institutional nursing home care.



The PAN Foundation is an independent, national 501 (c)(3) organization dedicated to helping underinsured people with life-threatening, chronic, and rare diseases get the medications and treatments they need by assisting with their out-of-pocket costs and advocating for improved access and affordability.

panfoundation.org

Supporting Literature

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