

The Caucus Corner

The National Caucus and Center on Black Aging, Inc. (NCBA)
 Monthly Newsletter
 November 2023

National Family Caregivers Month



National Family Caregivers Month will begin on Wednesday, November 1, and run through Thursday, November 30.

Celebrating Family Caregivers during National Family Caregivers Month enables all of us to:

- Raise awareness of family caregiver issues
- Celebrate the efforts of family caregivers
- Educate family caregivers about self-identification
- Increase support for family caregivers
- Reduce feelings of isolation

Caregiver Action Network is the organization that chooses how to celebrate National Family Caregivers Month annually and spearheads the celebration of NFC Month nationally. Each year, Caregiver Action Network makes materials available for general use, including the theme, a social media kit, etc. and coordinates with the Administration for Community Living and organizations across the field.

Caregiver Action Network (the National Family Caregivers Association) began promoting national recognition of family caregivers in 1994. President Clinton signed the first NFC Month Presidential Proclamation in 1997 and every president since has followed suit by issuing an annual proclamation recognizing and honoring family caregivers each November.

For more information about the National Family Caregiving month, visit:
<https://www.caregiveraction.org/national-family-caregivers-month>

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Who is Considered a Caregiver? Caregiver Statistics and Demographics

At some point in your life, you are likely to either become or need a caregiver. One in five adults in the United States is currently (or has been within the last 12 months) an informal caregiver. Caregivers are the often-forgotten backbone of our healthcare system. Without them, our medical system would grind to a halt.

The economic value of family caregivers is steadily increasing, with the most recent estimation valuing their (unpaid) contributions at approximately \$470 billion annually. In this article, we will define who is considered a family caregiver, explore trends in family caregiving, and discuss the typical activities a caregiver may partake in.

Are You a Caregiver?

An informal caregiver is someone who cares for an aging or ailing person without compensation. Here are a few quick questions to ask yourself to determine if you are a caregiver:

- Are you concerned about the health and well-being of a loved one and check in on them more frequently than you otherwise would?
- Do you help them with any of their daily life tasks such as errands, meal preparation, grooming, transportation, or medication disbursement?
- Do you provide physical, emotional, financial, or logistical support to this person?
- Or do you feel at all responsible for the health and well-being of this person?

If you answered yes to any of these questions, you are probably a caregiver. An informal or family caregiver in the state of California can be the child, spouse, domestic partner, parent, grandparent, grandchild, parent-in-law, or sibling of an aging or ailing adult.

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Caregiver Trends and Demographics

Here are some quick facts about the demographics of family caregivers in the United States.

- Approximately one in five people has provided unpaid care to another in the last 12 months in the United States.
- The vast majority of caregivers provide care to one other adult (82%), 15% of caregivers care for two adults, and 3% care for three or more adults.
- Almost one in four (24%) caregivers is a millennial. 40% of all caregivers are men, and about 40% of all caregivers are members of multicultural communities.
- The average family caregiver spends over \$7,000 annually out-of-pocket on care-related expenses.

For more information, visit:

<https://www.caregiveroc.org/post/caregiver-health-statistics-demographics>.

Caregiver Duties and Responsibilities

The daily life of a family caregiver may vary significantly from caregiver to caregiver. Some caregivers will be needed around the clock to provide care and support for their loved one. Others will be needed less frequently for help with tasks like transportation and errands. For others still, it may just mean being the person on-call—ready to show up at a moment's notice in an emergency. **Regardless of the level of commitment, if your loved one depends on you in any capacity, you are a family caregiver.**

Your individual responsibilities will vary depending on:

The ailment—if you're caring for someone with advanced Alzheimer's, for example, their needs may be more constant and demanding than someone caring for a loved one with a physical impairment.

Location and proximity—caring for a loved one who lives far from you may mean that your role is less hands-on than being a caregiver for someone who lives nearby.

The situation—many things can affect the level of care you provide or are expected to provide. These things include your cultural norms, the environment (a rural environment that may have fewer hospitals or amenities nearby, for example), the way the home is set up, (whether it is single-story and accessible or potentially hazardous, for example) what other obligations you have (work or children, for example), and who you can share the roles/responsibilities with (if anyone).

Daily Caregiving Tasks

Regardless of the situation, these are some common tasks caregivers are often responsible for managing:

- Transportation and errands
- Personal care and grooming (managing incontinence, bathing, dressing, etc.)
- Feeding and meal preparation
- Nutrition and health
- Medication reminders and dispersal
- Companionship and emotional support
- Housekeeping and maintenance
- Home safety (preventing slips, trips, and falls)
- Doctor's appointments (and becoming the patient's advocate)
- Emergency preparedness
- Physical exercise
- Insurance claims
- Communication with other family members and friends
- Financial obligations and bills
- Advanced directives
- Managing hydration
- And more.

Closing Thoughts

Becoming a caregiver, as you know, can take a lot out of you. It is a high-pressure role that many caregivers juggle alongside their other responsibilities, such as being a parent to a small child or a full-or-part-time job. The good news is that whatever your situation looks like, you are not alone.

For more information, visit:

<https://www.caregiveroc.org/post/who-is-considered-a-caregiver-caregiver-statistics-and-demographics>

Caregiver Health - Statistics & Demographics

According to a study by the National Alliance for Caregiving in 2020, 1 in 5 adults in the United States have provided care to a loved one in the last 12 months. The value of this unpaid labor force is valued at \$470 billion annually as of 2019.

The annual economic value of unpaid family caregivers is more than:

- All out-of-pocket spending on U.S. health care (\$366 billion in 2017).
- Professional home care services (\$97 billion in 2019).
- Total annual spending at nursing homes and continuing care retirement communities (CCRCs) (\$172.2 billion in 2019).

The Financial Impact of Caregiving

Evidence shows that most caregivers are ill-prepared for their role and provide care with little or no support. They are also often financially strained, with nearly half of caregivers reporting financial strain in one of the following areas according to AARP:

- The inability to save money
- Taking on more debt
- Using up personal savings
- Missing bills/late payments
- Needing to borrow money from friends or family.

Family caregivers, according to this same study, spend an estimated average of \$7000 per year in out-of-pocket expenses.

The Emotional Impact of Caregiving

- Caregivers are at an elevated risk of mental health problems.
- Roughly 20% of caregivers are clinically diagnosed with depression (twice the rate of the general population).
- An estimated 60% of caregivers show clinically significant signs of depression.
- Those caring for someone with dementia are at even higher risks of depression.
- Female caregivers are at an elevated risk of depression over male caregivers.

You are at a higher risk for mental health illness as a caregiver if:

- There is a chronic and progressive illness in a loved one under your care.
- Your care recipient shows abnormal, erratic, or disruptive behavior.
- Your care recipient has a cognitive impairment.
- They are under your care for a long period of time.
- The care recipient is your spouse.
- Your care recipient shows functional and/or physical deficits.
- You're caring for someone with a form of dementia (such as Alzheimer's disease).

The Physical Impact of Caregiving

Caregivers have lower levels of subjective well-being and physical health than noncaregivers with the greatest impact among caregivers treating patients with dementia.

"Caregivers are more stressed, depressed, and have lower levels of subjective well-being, physical health, and self-efficacy than noncaregivers."



How Can You Show Appreciation to a Family Caregiver?

To observe National Family Caregivers Month 2023, here are five things you can do to encourage and support a family caregiver in your life. However, you choose to show appreciation to a family caregiver during family caregiver awareness month, make a special effort to make life a bit easier for the family caregivers you know.

Provide Respite Care

If it's once a week or just once – period – caregivers can benefit greatly from a break from their work. Spend a morning with their loved one while they run errands or take some time for themselves. The gift of your time is priceless.

Check in Regularly

Let them talk about their experiences without offering advice or casting an opinion. Let them know that you see the work they are doing and the value it brings to the family and community. Remember, you don't have to fix their problems. Just being able to talk openly and without judgment is often the support they need.

Be Specific with Your Offers

Avoid saying "let me know if you need anything." Instead, make a specific offer of help. When caregivers are overwhelmed, it can be difficult to ask for help, so the more specific you can be, the better.

Help with Chores

Bring a meal, clean the house, help with laundry, do yard work, or tackle any other life tasks that are hard for caregivers to get to. This helps ease their burden and makes them feel supported.

Keep Inviting Them

Even if you know they can't attend an outing or gathering, continued invitations will make a caregiver feel less isolated and let them know that you are thinking of them and value their presence. And you never know when they might be able to make it happen!

Offer Encouragement

A thoughtful card or text message, or even a small gift, can show that you recognize the gift of their service. Be positive about how you appreciate their efforts and see what a great job they're doing.

According to [AARP](#), 1 in 4 caregivers (23%) find it difficult to take care of their own health while caregiving. 23% of caregivers also self-report that caregiving has made their health worse. This rate of physical health impact gets worse with time - the longer someone provides care, the worse their reported health gets.

Demographics of Caregiving

The caregiving community is heavily comprised of older females, though millennials are increasing their portion of this demographic.

- 67% of caregivers are female, only 33% are male.
- People of color make up a larger proportion of the caregiving community.
- The average caregiver age is 49.9 years old.
- 32% of caregivers have a child or grandchild at home in their care.
- 50% of caregivers work full-time while providing care.

Closing Thoughts

Caregivers are likely to be more stressed, anxious, or depressed than the general populace. They are also likely to experience financial strains and physical ailments or declining health due to stress during (and sometimes for years after) caregiving. While this situation may feel lonely, as a caregiver, you are not alone.

For further reading and resources, we invite you to check out our library of information for family caregivers by [clicking here](#). You are also welcome to give us a call at 800-543-8312 to find out more about how we can support you in your caregiving journey.

For more information, visit:

<https://www.caregiveroc.org/post/caregiver-health-statistics-demographics>



Caregivers Often Don't Identify With the Term

There is some confusion about what defines a caregiver – even among caregivers themselves. Caregivers often view their role as simply that of a daughter/son, spouse, parent, etc. who is “just doing their job” or “helping out.” A critical component of supporting caregivers is first understanding what the role entails.

Who is a Caregiver?

A caregiver is a person who provides care and assistance to another person with limitations related to illness, injury, or disability. The care recipient may have mobility limitations, dementia, behavioral or mental health conditions, developmental disabilities, or any situation (permanent or temporary) that means they need some level of assistance with daily living activities and other aspects of life.

What Does a Caregiver Do?

Caregivers may provide many different types of support, such as:

Personal care:

- Bathing, personal hygiene, dressing and toileting
- Getting in and out of bed or a chair and walking
- Meal preparation and feeding

Medical care:

- Organizing and giving medication
- Managing and attending appointments and maintaining medical records and information
- Managing therapies and treatments
- Arranging nursing and other medical supports
- Performing basic medical tasks

Other life management tasks:

- Shopping for food, clothing, and other essentials
- Providing transportation or organizing transport
- Managing finances, paying bills, planning for the future
- Housekeeping and home maintenance
- Managing communication with others
- Arranging respite care providers

Who Do Caregivers Care For?

Caregivers may be caring for:

- An aging parent, spouse or senior adult
- A minor child or adult child with disabilities or complex medical needs
- A spouse, sibling, family member or another individual with a chronic health condition or disability

What's the Difference Between Parenting and Caregiving?

Taking care of a typically developing child has its obligations and responsibilities, but for parents of children with developmental disabilities or chronic health issues, the responsibilities are often much more demanding and unpredictable. A parent who is also a caregiver is providing care to their child (of any age) who needs some degree of assistance beyond what is typical for a person of a similar age.

What's So Challenging About Caregiving?

When one person is dependent on another for daily living activities such as meals, transportation, arranging appointments and other personal care, the impact is significant and puts stress on all other areas of the caregiver's life.

Furthermore, many times caregiving doesn't have a definite rhythm or end – it's rife with unexpected events that need immediate attention, and it can last for years or even an individual's entire life.

What is a Caregiver-Friendly Workplace?

A caregiver-friendly workplace provides the flexibility and support to help employees keep their jobs while also taking care of their loved ones. With strong policies and practices, companies can reduce stress on their caregiving employees while also reducing absenteeism, turnover and healthcare costs.

- Caregivers suffer loss of wages, health insurance and other job benefits, retirement savings or investment, and Social Security benefits—losses that hold serious consequences for the “career caregiver.” In 2007, 37% of caregivers quit their jobs or reduced their work hours to care for someone aged 50+.
- 39% of caregivers leave their job to have more time to care for a loved one. 34% leave because their work does not provide flexible hours.
- 17% of caregivers of people diagnosed with dementia quit their jobs either before or after assuming caregiving responsibilities.
- 54% arrive to their place of work late or leave early, 15% take a leave of absence, and 9% quit their jobs to continue providing care.
- 10 million caregivers aged 50+ who care for their parents lose an estimated \$3 trillion in wages, pensions, retirement funds, and benefits. The total costs are higher for women, who lose an estimated \$324,044 due to caregiving, compared to men at \$283,716.
- Lost wages for women who leave the work force early because of caregiving responsibilities totals \$142,693.
- 47% of caregivers have an annual household income of less than \$50,000, with a median income of \$54,700. African American and Hispanic caregivers are more likely to have an annual household income below \$50,000 (62% and 61% respectively).
- A 2011 Gallup poll suggests that employers should provide the following:
 - An employee assistance plan to promote discussions about emotional distress experienced by the working caregiver.
- Access to health counselors or “ask a nurse” for information on the care receiver’s condition.
- Access to counselors or others to make referrals and give advice about assisted living or nursing homes.
- 2 out of 3 caregivers support additional policy proposals preventing workplace discrimination against employees with caregiving responsibilities. [National Alliance for Caregiving and AARP.

Impact on Working Female Caregivers

- Working female caregivers may suffer a particularly high level of economic hardship due to caregiving.
- Female caregivers are more likely than males to make alternate work arrangements: taking a less demanding job (16% females vs. 6% males), giving up work entirely (12% females vs. 3% males), and losing job-related benefits (7% females vs. 3% males).
- Single females caring for their elderly parents are 2.5 times more likely than non-caregivers to live in poverty in old age.
- Employed caregivers are less willing than non-caregivers to risk taking time off from work; 50% seek an additional job and 33% seek a job to cover caregiving costs.

Annual Income

- The lower the income and education a person has, the more likely he or she is a caregiver. Similarly, those with a high school education or less (20%) take on a caregiver role versus 15% of college graduates and 16% of postgraduates.



**For more information, visit: Family Caregiver Alliance National Center on Caregiving,
<https://www.caregiver.org/resource/caregiver-statistics-work-and-caregiving/>**



Caring for Others is Stressful

More than one in five Americans today are caregivers, providing care and support to an adult or child with special needs. That is 21.3 percent of the population caring for someone in some way, somewhere across the nation. And in that population of family caregivers, four in 10 – roughly 38 percent - find their situation extremely stressful.

We all experience stress in our lives, but going beyond stress, according to [Caregiver.org](https://www.caregiver.org), which has called caregiver depression an all-too silent health crisis, 20 percent of family caregivers suffer from depression. To put that into perspective, that is twice the rate of the general population reporting depressive disorders.

Anxiety BIG also comes into play for a lot of caregivers. Managing too many responsibilities, feelings of not being in control of the situation, fear for a loved one's well-being, and financial and healthcare coverage stressors can bring on various states of anxiety in a caregiver. In addition, caregivers spend many more hours a week providing care than a typical profession and report employment problems, health issues, lack of sleep and little time to do the things they enjoy.

The Caregiver Story

ADAA is committed to amplifying the voices of diverse people and communities. Depression, anxiety, and other related mental health disorders can affect anyone regardless of background or profession. If you are a caregiver and would like to share your story, ADAA would like to hear from you: **Find out how to share your story with ADAA by visiting: <https://adaa.org/understand-anxiety-depression/share-your-story>.**

When Should a Caregiver Seek Care?

We at ADAA understand that being a caregiver, whether by profession or a desire or duty to care for family and friends, can be extremely rewarding, not to mention admirable. But it is physically and mentally exhausting and can take a toll on one's emotional wellbeing.

If you are a caregiver, you probably often put others' needs before your own. Sacrificing your own time, energy and physical and emotional needs can be draining. Most caregivers will feel overwhelmed, stressed, anxious and probably even sad at some point, but if those feelings get to a stage where they affect your quality of life and you have difficulty functioning day to day (understanding anxiety & depression), it's time to seek care for yourself.

Always consult your doctor or contact a mental health provider if you feel you are experiencing any signs or symptoms of a mental health condition, especially if symptoms persist for two or more consecutive weeks. And remember that you cannot take care of anyone if you don't take care of yourself first.

Support for Caregivers

It's important to find resources and people that make you feel supported. **To learn about the caregiver support in your state, visit: <https://www.aarp.org/caregiving/local/info-2021/state-caregiver-resources.html?cmp=RDRCT-bc951712-20210305>**

3 Important Reasons to Bring Your Medications to all Medical Appointments

Consider this scenario: It's a Sunday morning, and you've awoken with a fever and sore throat. Given the day, you know that your primary care physician (PCP) is unavailable, but you want to feel better fast.



So, rather than waiting until Monday to try and get an appointment, you walk-in to an urgent care facility. The doctor there writes you a prescription and sends you on your way. Did you tell them every other medication (both prescription and over the counter) that you take along with your specific dosage and frequency? When you see your PCP next, do you mention the urgent care visit and the prescription given to you there?

While you may have attempted to recount all of your medications, unless you had them or a detailed list with you, chances are that you forgot one or two or perhaps gave an inaccurate dosage. It's a common situation that both healthcare providers and patients frequently encounter, and it is one that is becoming increasingly problematic.

As of 2015, adverse drug events (ADE) accounted for around **700,000 emergency room visits and nearly 100,000 hospitalizations**. In many of these cases, medication reconciliation between patient and physician could have helped avoid the event entirely. Whether seeing your PCP, an urgent care doctor, emergency room physician, or **cardiologist**, bringing your medications along will help them provide you with the best care possible and avoid any of the following medication reconciliation problems.

Medication Duplications

Duplicate therapy occurs when a patient takes at least two separate medications from the same class, whether over the counter or prescription. If your physician is unaware of all of the medications that you are taking on your own or that have been prescribed by another doctor, he may unknowingly write another prescription for the same or a similar drug. Depending on the type and dosage of medication, serious problems, including emergency situations may result.

Medication Dosage Errors

Past studies have indicated that **improper dosage of medications accounted for the highest volume of medication errors and related fatalities**. You can do your part to avoid these complications by ensuring that each and every doctor you see is aware of not only which medications you regularly take, but also how much and how often. No matter how well you think you know your prescriptions, there is always the possibility of forgetting the name or confusing your dosage amount.

Medication Interactions

There are many drugs that have the potential for adverse interactions. While you may not think that your daily medications are risky or worth mentioning, your healthcare team of doctors and nurses have more intimate knowledge of the potential dangers. No matter how innocent or unimportant it may seem, bringing even the most common medications can help your provider avoid a dangerous situation where drugs are unfavorably mixed.

Bring all medications to each and every appointment for a thorough review with your physician. Even the slightest change in one medicine may impact the others. You will never regret bringing them and having the peace of mind that comes along with it.

For more information, visit: <https://www.cardio.com/blog/3-important-reasons-to-bring-your-medications-to-all-medical-appointments>



For Rural Caregivers, Respite Can Be Hard to Come By

Rural caregivers may be more likely to experience an increase in caregiver burden than urban counterparts

When caregivers in rural Washington County, Maine, look for help to lighten their load, they might have a hard time. Home care aides are in short supply in the smaller communities of the state's eastern region. Adult daycare services can offer caregivers a few hours to run errands or take a break, but the nearest center could be a long journey away for rural residents.

"When you're talking about a two-to-three-hour drive one way, and you're adding that into an already busy schedule, it's just not going to be possible," says Jami Aleksiev, who, as community services director for the Eastern Area Agency on Aging, helps to connect caregivers in four Maine counties with programs that can relieve them.

How to support caregivers outside of America's urban centers is a pressing question. The population in remote areas is growing older. As of 2021, 20% of Americans living in rural regions are over 65, compared to 16% in more urban areas.

While stress, isolation and lack of support can be challenges for caregivers who live anywhere, those factors can be exacerbated for people who care for friends and family members in rural communities.

In Maine, which ranks demographically as the oldest and one of the most rural states in the country, older adults' networks in the community are often diminished, explains Lenard Kaye, director of the University of Maine Center on Aging and a professor of social work.

Many young people leave their rural hometowns for bigger cities, often out of state. Unfortunately, that means fewer options when an older person needs care. "Immediately available, locally residing individuals who can assist are at a premium," says Kaye. "But yet it remains a family affair, putting those who are locally situated under the gun to step up and deliver it under whatever stress and strain they may feel."

Seeking Help at Home

Unpaid caregivers — including family members and friends — provide about 80% of care at home in the U.S. One option that can give those unpaid caregivers a break is to have a professional, like a home care aide, come in to take on some of the tasks, either paid through public programs or out of pocket.

But in Maine, as across the U.S., there is a strong need for more direct workers. That's true of many rural areas. Nationwide, a 2023 study found 32.9 home health aides for every 1,000 adults 65+ in rural areas, compared to 50.4 for every 1,000 older urban residents.

In Maine, the direct care sector's challenges significantly impact the services available for older adults, people with physical and intellectual disabilities, and more. For example, the state's nursing homes are operating at three-quarters capacity.

In addition, a third of people enrolled in a state program for home care for older adults are either overstaffed or only getting part of the time they're eligible for. For family caregivers in Eastern Maine, location, pay rates and specialized needs — like dementia — can make it hard to find professionals for home care, according to Aleksiev.

Some workers take on jobs knowing they'll have an hour's commute. "For some, it is just so rural, there's just nobody around that can travel to where people are," she says. Even in Maine's more populated areas, the need for more workers is challenging.

Ann Marie Kane, who goes by a.m.k, lives with and cares for her mother in a suburb of Maine's largest city, Portland. She can hire a trained home care worker for 15 hours a week through a program she's enrolled in. But she hasn't been able to find anyone. "I would love to have somebody," a.m.k says, "and the bigger picture is it would be great for my mom to have somebody hanging out with her that's not me."

In the greater Portland area, a.m.k. says she has found some programs to support her mom, who has a neurological condition. Her mother attends an adult day service and goes indoor rock climbing with Maine Adaptive Sports. A.m.k. has found connections with fellow caregivers through social media and a support group run by a local agency. But the emotional toll of caregiving is heavy. "It's a really bad double-edged sword because you spend all this time trying to improve their daily life as they're declining," a.m.k. says. "One of the issues to deal with as a caregiver is that we are live grieving every day, because we're watching our loved ones just lose, every day, a little bit and a little bit more."

Need for Respite

A Canadian study found that though caregivers in rural areas reported having support from community members, they also cope with loneliness and anxiety and have less access to health care and social services. Further, during the COVID-19 pandemic, a survey in the U.S. found that rural caregivers for family and friends were more likely to report a significant increase in caregiver burden than urban counterparts.

Aleksiev says offering caregivers' reprieve is one way the agency supports people caring for family members and friends in eastern Maine. EAAA facilitates various programs, including Meals on Wheels, Medicare counseling and caregiver training. Aleksiev says whenever someone reaches out about one of their programs, the agency tries to connect them with other services that suit their situation, including ways to support caregivers.

While many people the agency works with are around Bangor, family care specialists reach out to rural residents in any way they can — including visiting vet clinics, town offices and medical facilities to meet community members. One option that can help caregivers is a new statewide pilot program launched last fall, Respite for ME, which gives eligible caregivers \$2,000 to use in a way that will give them a break. In winter, some people used the funds for snow plowing. In the summer, yardwork is popular. The flexibility allows caregivers to get a break, whatever works for them. "Respite looks different for everybody," Aleksiev says.



While stress, isolation and lack of support can be challenges for caregivers anywhere, those factors can be exacerbated for people in rural communities. | Credit: Getty

Kaye of the University of Maine says payment for caregiving services and respite are two of the top needs for rural informal caregivers. His research found that caregiving is a second job for many in rural areas.

A "stiff-upper lip" mentality means they often keep their caregiver roles private. There's often hesitation to share their situation with employers for fear that it can lead to negative consequences. Rural caregivers tend to be lower income, he says, and they often face their own health issues. "Caregiving is a lonely and isolating and disconnecting task and experience and can drag on for years."

Informal institutions in small communities can be a way to build up a network to support caregivers, he says, drawing on existing rural hubs like churches and synagogues, lunch clubs and community centers. In general, Kaye says, raising awareness about the realities of caregiving among the public more broadly could help more people be prepared for the experience.

Adds Kaye, "We would benefit greatly from more preparation and more appreciation for the complexities and the responsibilities that caregiving gives, such that we don't minimize it and we appreciate the fact that it's likely going to be knocking at each and every one of our doors at some point in our lives."

Contributing Author: [Elizabeth Hewitt](#) is an American journalist based in the Netherlands, reporting on topics including aging, nature, and culture. Her stories on dementia have appeared in publications including *Being Patient*, *Reasons To Be Cheerful* and *Sierra Magazine*, and she's a former editor and reporter for the Vermont nonprofit news site [VTDigger.org](#)

GRANDFAMILIES

A New Generation of Caregivers: Grandchildren Taking Care of Grandparents

A new generation of young people is stepping up to help their aging and ill family members. Although the [Caregiving in the U.S. 2020](#) report found that the average age of family caregivers (49.2 years old) remains essentially unchanged since the last report in 2015, the data also reveal that 24 percent of informal caregivers are between the ages of 18 and 34. Millennials and members of Generation Z are aging into the caregiving role. While most caregivers ages 18 to 49 are caring for a parent or in-law, 17 percent report taking care of grandparents or grandparents-in-law.

Why Are More Grandchildren Caring for Grandparents?

Family and household composition have changed a great deal over recent decades. Many of these young caregivers have lived with or been raised by their grandparents. For example, a 2021 [report](#) published by Generations United found that more than one in four Americans (26 percent) are living in a household with 3 or more generations. In other instances, a grandchild becomes the primary caregiver because he or she lives nearer to the elder than other family members. Sometimes, it's simply because a particular grandchild feels close to the grandparent and has the so-called "caregiver personality."

There are countless factors that influence why a grandchild might become the primary caregiver for one or both grandparents, but the underlying reason for this is usually that the elder's own adult children are not willing, able or alive to assume this role.

Younger Caregivers Face Significant Challenges

Few people with first-hand experience caring for an elder would describe it as an easy job. But consider the fact that most family caregivers are age 50 or older. They were probably able to enjoy their teenage and early adult years, eventually joining the workforce, learning to fend for themselves, getting married and raising children. What I'm trying to convey is that the average family caregiver has a few decades' worth of knowledge, adult living, and real-world experience under their belt.

The same cannot be said for caregivers in their 20s. Their friends are in college, working odd jobs or starting careers. They have active social lives and can go out for some fun at a moment's notice. Perhaps they're even getting married, settling down and starting families. Caregiving, however, probably isn't even on their radar at this young age.

A grandchild who is taking care of Grandma and/or Grandpa may also be juggling school, work, or both. Unlike their peers, though, any "extra" time they have is spent managing medications, assisting with **activities of daily living** (ADLs), driving to doctor's appointments, cooking meals, doing laundry and spending time with their grandparent(s). These young people are on the same 24/7 emotional rollercoaster that we older caregivers find so exhausting, but they have far fewer understanding peers from whom they can get support.

After too many "Sorry, but I have to take care of Grandma" excuses, friends stop calling. After too many instances where caregiving interferes with attendance and the ability to concentrate, many drop out of school or struggle to hold a job. These young people who are just starting out and supposed to be building a strong foundation for the rest of their lives are instead making life-altering sacrifices for those they love.

Isolation is often the result. Feelings of loneliness are associated with higher levels of emotional stress and physical strain, leaving younger caregivers particularly vulnerable to **caregiver burnout**. Respite care is touted as the solution for those who are struggling to balance caregiving responsibilities and self-care. However, grandchildren often take on this role because their grandparents have few or no other family members to rely on and refuse to consider other sources of support. In fact, more than half (58 percent) of Generation X caregivers report feeling they had no choice in assuming this responsibility.

When it comes to managing a grandparent's care, younger caregivers may also experience more pushback and less cooperation. While Grandma or Grandpa may be grateful for the daily assistance and company a grandchild provides, they might not see the validity of a youngster's involvement in important matters like legal and financial planning and health care decisions.

Elders are notorious for disregarding their adult children's requests and suggestions to engage in estate planning, **give up the car keys** or go to the doctor.

Taking directives from someone who is two generations younger typically does not go over well either. It can be incredibly frustrating for a family caregiver of any age to shoulder such a heavy burden but have little or no actual say in care decisions that directly affect their lives and ability to help their loved ones.



Hiring in-home care, taking a grandparent to adult day care, or encouraging them to move to a senior living facility are all options that can help a grandchild achieve a better balance in life, but they face obstacles here, too. Their elder may not have the resources to cover these costs or they may flatly refuse to pay for their own care.

This leaves a grandchild with a very difficult choice: either muddle through without any help or find a way to cover these costs themselves. Young adults who are relatively new to the workforce typically don't have savings that they can fall back on, and diverting income to pay for respite care can have a detrimental impact on their financial situation. Ask any middle-age caregiver—it can take years to get back on track after covering these costs for a loved one. Many never fully recover enough to plan financially for their own retirement and long-term care.



Resources for Grandchildren Taking Care of Elderly Grandparents

As the provision of long-term care increasingly shifts from residential facilities to home and community-based care, supportive services become more and more important for seniors and family caregivers of all ages. The following resources can help younger caregivers protect their physical, mental, social, and financial health and find ways of supporting their grandparents without jeopardizing their futures.

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1. AREA AGENCIES ON AGING (AAAs)

AAAs provide information, assistance, and referrals to community services for seniors, individuals with disabilities and family caregivers.

2. CAREGIVER SUPPORT GROUPS

Whether in person or online, participating in a caregiver support group is an excellent way to connect with other people who understand the unique challenges you're facing, get advice, and discover new elder care resources, products and solutions. The Caregiver Forum even has a dedicated section for questions and discussions about caring for grandparents.

3. GOVERNMENT RESOURCES

There are countless federal, state, and local programs available to seniors and family caregivers. Even benefits or services that aren't directly related to elder care can reduce financial strain and help a caregiver carve out time for respite.

4. DISEASE-SPECIFIC NONPROFIT ORGANIZATIONS

An elder's unique health conditions have a significant impact on the type of care and assistance they require. Organizations like the Alzheimer's Association, the American Cancer Society and the Parkinson's Foundation are valuable sources of information and support pertaining to these specific medical issues.

5. BOOKS ON CAREGIVING

If you're looking for a new perspective on aging, tips for communicating with elders, advice on setting boundaries or valuable insights on dementia care, pick up one of these acclaimed books for caregivers.

6. EXPLORE RESPITE CARE OPTIONS

From in-home care to nursing homes, learn about the different types of elder care available to support your grandparent and help you enjoy a break from caregiving.

The Meaning of Caregiver

Caring for another is a choice straight from the heart,
Always ready to provide the need and play this special part.
Reality is that the job is not an easy one,
Every day is filled with challenges that must be met and done.
Giving of yourself as nurse or friend as needs demand,
It seems you have been blessed with a special set of hands.
Very soft or very strong- these hands can change so fast,
Exceeding all the expectations and putting themselves last.
Reaching out to comfort day or night, whatever the role,
The Caregiver was created with a truly special soul.

By Michell Price

One's youth should be spent following dreams, gaining experience, cultivating friendships, and building a future.

Whether you volunteered for this role or feel thrust into taking care of your grandparent(s), it's important to remember that your needs and goals matter, too. Grandma and/or grandpa already got to enjoy this crucial time in their life and should want you to do the same. Don't let guilt, embarrassment or fear prevent you from asking for help. With the right resources and assistance, you can learn to balance caregiving with your own life.

For more information, visit:

<https://www.agingcare.com/Articles/grandchildren-caring-for-their-grandparents-149490.htm#:~:text=In%20other%20instances%2C%20a%20grandchild%20becomes%20the%20primary,the%20grandparent%20and%20has%20the%20so-called%20%E2%80%9Ccaregiver%20personality.%E2%80%9D>



Founded in 1970, The National Caucus and Center on Black Aging, Inc. (NCBA) is a national 501 (c) (3) nonprofit organization. Headquartered in Washington, DC, NCBA is the only national aging organization who meets and addresses the social and economic challenges of low-income African American and Black older adults, their families, and caregivers.

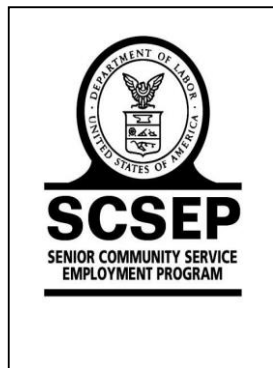
NCBA Supportive Services include:

Job Training & Employment

NCBA administers Senior Community Service Employment Program (SCSEP) with funding from the U.S. Department of Labor (DOL) to over 3,500 older adults, age 60+ in North Carolina, Arkansas, Washington, DC, Illinois, Missouri, Michigan, Ohio, Florida, and Mississippi.

SCSEP is a part-time community service and work-based job training program that offers older adults the opportunity to return or remain active in the workforce through on the job training in community-based organizations in identified growth industries.

Priority is given to Veterans and their qualified spouses, then to individuals who: are over age 65; have a disability; have low literacy skills or limited English proficiency; reside in a rural area; may be homeless or at risk for homelessness; have low employment prospects; failed to find employment after using services through the American Job Center system.



Annually, NCBA and CVS partner to host job fairs to orient SCSEP participants about the benefits of working at CVS as a mature worker.

To learn more about the Senior Community Service Employment Program (SCSEP), visit: <https://ncba-aging.org/employment-program-resources>

NCBA administers the Environmental Employment (SEE) Program with funding from the U.S. Environmental Protection Agency.



Agency (EPA) to older adults, age 55+ with professional backgrounds in engineering, public information, chemistry, writing and administration the opportunity to remain active in the workforce while sharing their talents with the U.S. Environmental Protection Agency (EPA) in Washington, DC, and at EPA Regional Offices and Environmental Laboratories in NC, OK, FL, and GA.

To learn more about the Senior Employment Environment Program (SEE), visit: <https://www.ncba-aged.org/environmental-employment-program-resources>



Health

The NCBA Health and Wellness Program offers continual education, resources, and technical assistance either in-person, online, or through self-paced learning opportunities. The program offers a wide variety of social and economic services and support including, the delivery and coordination of national health education and promotion activities, and the dissemination of and referral to resources.

To learn more visit <https://ncba-aging.org/health-and-wellness>



BREAKING NEWS

[FIVE BENEFITS YOU CAN APPLY FOR USING SSA.GOV](#)

We continue to make it easier for you to access our programs and benefits. Our website offers a convenient way to apply for benefits online.

Here are 5 ways you can apply for benefits using ssa.gov.

- **Retirement or Spouse's Benefits** – You must be at least 61 years and 9 months and want your benefits to start in no more than 4 months. Apply at www.ssa.gov/retirement.
- **Disability Benefits** – You can use our online application, available at www.ssa.gov/benefits/disability to apply for disability benefits if you:
 - Are age 18 or older.
 - Are not currently receiving benefits on your own Social Security record.
 - Are unable to work because of a medical condition that is expected to last at least 12 months or result in death.
 - Have not been denied disability benefits in the last 60 days. If your application was recently denied, our online appeal application is a starting point to request a review of the determination we made. Please visit www.ssa.gov/apply/appeal-decision-we-made.
- **Supplemental Security Income (SSI)** – SSI provides monthly payments to adults and children with a disability or blindness who have income and resources below specific financial limits. SSI payments are also made to people age 65 and older without disabilities who meet the financial qualifications. If you meet certain requirements, you may begin the process online by letting us know you would like to apply for SSI at www.ssa.gov/ssi. If you do not have access to the internet, you can call your local Social Security office to make an appointment to apply.
- **Medicare** – Medicare is a federal health insurance program for:
 - People age 65 or older.
 - Some people younger than 65 who have disabilities.
 - People with end-stage renal disease or Amyotrophic lateral sclerosis (ALS).

If you are not already receiving Social Security benefits, you should apply for Medicare 3 months before turning age 65 at www.ssa.gov/medicare.

- **Extra Help with Medicare Prescription Drug Costs** – The *Extra Help* program helps with the cost of your prescription drugs, like deductibles and copays. People who need assistance with the cost of medications can apply for *Extra Help* at www.ssa.gov/medicare/part-d-extra-help.

Please share this information with those who need it.



“Pharmacy deserts have been a longstanding issue that has gotten worse with recent closures of both independent and chain pharmacies,” said Dima Qato, an associate professor at the University of Southern California School of Pharmacy, who studies disparities in geographic access to pharmacies and spent more than a decade working as a community pharmacist in Chicago. That lack of access can have major consequences for the health of people living in marginalized communities.

How pharmacy deserts impact people’s health

A 2021 study co-authored by Qato, published in [Health Affairs](#), examined disparities in pharmacy access in major cities such as Los Angeles, Chicago, Houston and Memphis. In Los Angeles, one-third of all Black and Latino

neighborhoods were pharmacy deserts — meaning that the average distance to the nearest pharmacy was 1 mile or more. The biggest racial gap in pharmacy access was in Chicago, where only 1% of white neighborhoods were pharmacy deserts, compared to 33% of Black neighborhoods in the South Side.

Rural and suburban areas qualify as pharmacy deserts if the nearest drugstore is more than five or two miles away, respectively, Qato said. However, the radius drops to just half a mile in low-income neighborhoods with low vehicle ownership, as it can be hard for residents to walk or take public transportation to the nearest pharmacy. “When pharmacies close, there’s some people who stop taking their medications — especially if they live in pharmacy deserts. Others may take time off work or delay picking up their prescriptions,” said Qato.

Many Cities Have Pharmacy Deserts

In an earlier study of 3 million adults, published in [JAMA Network Open](#), Qato and her colleagues found that when pharmacies close in a community, older adults are more likely to stop getting their prescriptions filled for vital heart medications such as statins, beta-blockers, or oral anticoagulants.

Pharmacy deserts can take a particular toll on Black, Latino, low-income, and uninsured households because these groups are already at higher risk of chronic disease, said Juan Tapia-Mendoza, a community pediatrician who practices in Washington Heights in New York City. “Now it’s harder for them to access the prescription medications they rely on to treat common chronic diseases such as diabetes, heart disease, and arthritis.”

People living in pharmacy deserts also have more limited access to flu shots and vaccines for Covid-19. That’s a particular problem at a time when many community doctors and health facilities have not yet received the latest Covid vaccine, leaving patients in underserved areas with few alternatives, experts tell STAT. “Pharmacies were crucial in Covid vaccine rollout,” said Utibe Essien, an assistant professor of medicine and a health disparities researcher at the University of California, Los Angeles.

Given longstanding vaccine hesitancy among Black and Latino communities, making immunizations even harder to access puts this already-vulnerable population at higher risk. “We’re talking about a community that has been historically terrorized by homeland security, immigration and customs enforcement, and the police. There’s already an inherent fear to seek medical help because they think that somehow the information, they provide is going to be used against them,” said Tapia-Mendoza.

In the South Side, Johnson received her flu vaccine at her local church, which transformed into a mass vaccination clinic in collaboration with a health center. This site has been imperative to making vaccines accessible for people in her community, she said, so they don’t have to travel to a pharmacy.

Why pharmacies like CVS, Walgreens, and Rite Aid are closing stores

Often, the decision to close a chain pharmacy store is purely a business one — albeit without the effects on communities in mind, said Tapia-Mendoza. Rite Aid spokesperson Alicja Wojczyk told STAT in a statement that as part of its bankruptcy process, “we notified the Court of certain underperforming stores we are closing to further reduce rent expense and strengthen overall financial performance.”

Walgreens spokesperson Kris Lathan told STAT that the company takes several factors into account when closing locations, “including our existing footprint of stores, dynamics of the local market, and changes in the buying habits of our patients and customers.” Lathan also noted that Walgreens has partnered with local churches and civic groups to “offer off-site and mobile clinics in neighborhoods and rural areas where we’re able to provide walk-up access to life-saving immunizations.”

CVS declined to comment on how it makes decisions about store closures.

Independent pharmacies struggle to stay afloat

The problem of closures isn’t just limited to major retail pharmacy chains. A [JAMA Internal Medicine](#) study published by Qato and her colleagues found that one in eight pharmacies closed during the six-year period between 2009 and 2015. According to their analyses, independent pharmacies in both urban and rural areas were three times more likely to close than chain pharmacies.

“I’ve been in Washington Heights for 30 years and the pharmacists that served my patients practiced in the independent pharmacies,” said Tapia-Mendoza. Smaller, independent pharmacies started to go out of business when the big retail giants entered the community over the past 10 to 15 years, he noted.

Many health plans also steer people toward their “preferred” pharmacies where drugs are cheaper and copays are lower, Qato noted: “Independent pharmacies are often excluded from networks, which results in patients going to chains.”

The majority of independent pharmacies’ earnings come from reimbursements they receive for filling prescriptions. Another issue, according to Qato, is that pharmacies at higher risk of being closed are those with a large customer base on public insurance like Medicare and Medicaid, which have lower reimbursement rates than private health plans. Compounding the problem is that pharmacy benefit managers often wind up under-paying pharmacies through low and delayed reimbursement rates. “Due to the lack of PBM regulations, independent pharmacies are closing more in low-income communities of color, which we know are disproportionately publicly insured,” said Qato.

Independent pharmacies are also often excluded from the 340B drug pricing program, a federal program that requires manufacturers participating in Medicaid to sell drugs at substantial discounts to hospitals or clinics, experts told STAT. “These hospitals and clinics often contract with large chain pharmacies that charge payers non-discounted prices for prescriptions filled,” said Qato. “The revenue derived from the drug sales is then distributed to both the

Between 2006 and 2019, the number of contract pharmacies grew in affluent and predominantly white neighborhoods, and declined in socioeconomically disadvantaged and Black and Latino neighborhoods, according to a study in [JAMA Health Forum](#). “We have preliminary data that suggests that 340B contract pharmacies are more protected from closure,” said Qato.

All this is particularly troubling because people who have been historically neglected by the U.S. health care system often trust independent pharmacies over bigger chains. “These pharmacists are from the community they serve and will employ staffers that are bilingual to deliver culturally competent care to our patients,” Tapia-Mendoza said.

When Johnson was growing up in the South Side of Chicago, she recalls going to a locally owned pharmacy, where the pharmacist ended up becoming friends with her mother. “The pharmacist got to know her and took good care of her whenever she needed counseling or getting her prescription refilled,” she said. “It was so much easier to go to a pharmacy when there was a personal connection than nowadays where pharmacists don’t even explain anything.”

From mobile pharmacies to free over-the-counter drugs

The few pharmacies that do remain in the South Side are often overburdened and unable to keep up with demand. “I never visit my closest pharmacy because I never usually get my prescription filled on time or find any over-the-counter medications, since they’re all out of stock,” Johnson said.

Another common issue in pharmacy deserts is that the few that are available often operate under limited hours. “In Washington Heights, there’s only one pharmacy open past 9 o’clock at night. All of the other pharmacies close by 8 or 9 p.m.,” said Tapia-Mendoza. That’s a particular disadvantage for patients living in low-income communities and communities of color, who often work long hours or multiple jobs and may not be able to get their prescriptions filled promptly.

More efforts need to be made to encourage pharmacies to stay open in these communities, experts told STAT. Increasing Medicaid and Medicare pharmacy reimbursement rates for prescription medications might be a start, but policymakers also need to make sure that stores serving Black and Latino communities are not excluded from health plans’ pharmacy networks.

“Both independent and chain pharmacies serving pharmacy desert neighborhoods within a plan’s service area should be included in the plan’s preferred pharmacy network,” said Qato. “Such regulations would ensure pharmacies serving disproportionately low-income, publicly insured populations are included in a plan’s preferred network and, in turn, these pharmacies — which are often the nearest pharmacies to pharmacy deserts and most at-risk for closure — can be used to fill prescriptions for the community.”

In the absence of typical brick-and-mortar pharmacies, other alternatives seek to meet patients where they are. In Connecticut, for example, Yale School of Medicine researchers have opened up the first mobile pharmacy in the state. The project, known as InMOTION, aims to bring care to people who are at risk of or living with infectious diseases, such as HIV, as well as those with substance use disorders, such as opioid use disorder.

“HIV treatment requires taking antiretroviral medications for life. People living with HIV may delay their medications if they don’t have access to reliable transportation or don’t have a walkable pharmacy nearby,” said Sandra Springer, leader of the InMOTION project and professor of medicine at Yale School of Medicine. InMOTION also partners with community health workers to identify people who do not have HIV and are eligible to receive pre-exposure prophylaxis (PrEP), which helps prevent the virus, said Springer.

Connecticut is currently the only state in the U.S. where mobile retail pharmacies are legal. Springer and her colleagues worked with state legislators to pass a law allowing drugs to be dispensed in locations beyond their designated storefronts.

In some parts of the country, community physicians like Bernadette Lim have taken matters into their own hands. Lim is the founder of Freedom Community Clinic in Oakland, California, an initiative that provides community-centered services free and/or at community scale to underserved communities in the Bay Area. To expand the clinic, she and her team are opening up a completely free pharmacy in spring 2024 with over-the-counter medications and contraceptives. “For a lot of people, there is not enough trusted information out there on medications,” she said. “In different grocery stores and retail pharmacies, Black and Brown people don’t find themselves safe or find medications accessible.”

Lim acknowledges that such measures won’t solve the larger issue of pharmacy deserts across the country. “People need pharmaceuticals, especially for very acute and chronic conditions. And if you have an interruption to that, then it literally then causes emergencies to happen.” Ultimately, experts say, lack of access to a nearby pharmacy is a human rights issue. “When closing a pharmacy, it means closing an epicenter that provides access to lifesaving medications, contraceptives, and vaccines,” Qato said. “The mass closure of pharmacies fail vulnerable communities.”



Doctors, CDC Recommends Three New Shots to Protect Older Americans' Health

Persons aged 65 and older are being urged to take a trio of new vaccines to guard against a resurgence of Covid-19, influenza, and RSV, a virus that can cause serious respiratory illnesses in very young children and older people.

The new Covid vaccine was formulated to combat the predominant variant of the coronavirus, which has significantly reduced its threat to public health since the start of a pandemic in 2020. However, the Centers for Disease Control and Prevention (CDC) says the virus remains in circulation and can still wreak havoc on Older Americans and anyone with underlying conditions such as asthma, diabetes, heart disease, and lung disorders, regardless of age.

In a departure from prior years, the 2023 Covid immunization will involve only one shot, once a year, like the annual flu vaccine, a welcomed departure from the multi-shot and booster protocols of 2020-2022. The RSV immunization involves one shot every two years or longer.

In most cases, doctors say, a person can get both the Covid and flu shots in the same visit. However, persons 85 and older are cautioned to check with their physicians before taking both vaccines at once.

"The new updated Covid-19 vaccine is the most effective way to give your body the ability to keep the Covid virus from causing you harm," said CDC Director Dr. Mandy Cohen. "This recommendation was based on extensive data and clinical trials."

All three of the vaccines are widely available at pharmacies, doctors' offices, and clinics and are covered by Medicare, Medicaid, and most private health insurers with no co-pay from patients.

Like before, the CDC notes that no vaccine provides absolute immunity against disease, but they can drastically reduce the severity of an illness and avoid hospitalization for those who become infected.