The Realities of Caregiver Stress



Discover how providers and facilities can recognize stress in family caregivers and provide resources to alleviate and prevent burnout to improve patient care.



The Realities of Caregiver Stress

Discover how providers and facilities can recognize stress in family caregivers and provide resources to alleviate and prevent burnout to improve patient care.

> St. Croix Hospice Chief Medical Officer Andrew Mayo, M.D.

> > Sponsored by



To learn more, contact us at: info@stcroixhospice.com 855.278.2764 stcroixhospice.com The number of older Americans is increasing rapidly and so is the number of family members serving as caregivers. Over the past 100 years, the number of people aged 65 and older grew almost five times faster than the total population. The population of adults aged 65 and older reached 55.8 million in 2020. That number is expected to reach 80 million by 2040.

As people age, their healthcare needs change. Many older people need help from loved ones who serve as caregivers in their daily lives. A 2020 "Caregiving in the U.S." report from the American Association of Retired Persons (AARP) found that nearly 42 million people were caregivers for a family member or friend aged 50 or older.

Healthcare providers and facilities are in a powerful position to support family caregivers and can help provide resources that alleviate caregiving stress. It is important that providers learn about trends in family caregiving, recognize the signs of caregiver stress and are knowledgeable of effective stress-relief strategies they can share.

Caregiver classifications

There are two broad categories of caregivers: formal and informal.

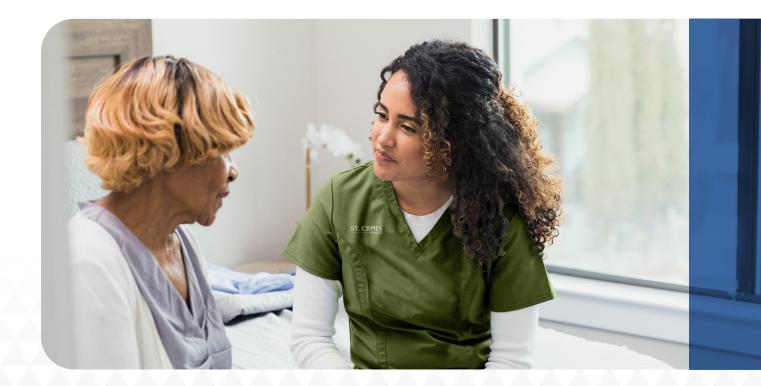
Formal caregiver

A formal caregiver is a paid professional or volunteer—often a nurse, doctor, or home health aide—who provides care in the home, hospital, or other healthcare setting. Caregiver requirements vary from state to state, but formal caregivers usually have at least a basic certification.

Family caregiver (informal caregiver)

A family caregiver, also known as an "informal caregiver," is usually a friend or family member. The AARP reports that at least 53 million people provide informal, often unpaid, care to older adults and disabled people of all ages. Most family caregivers are between the ages of 50 and 64, followed by ages 18 to 34, according to the AARP's report. Often, family caregivers are not only caring for aging parents or family members but for their own children as well. This is called "sandwich" caregiving.

Family caregivers may provide care in their own homes or in the patient's home. They may also support the patient's care in other healthcare settings, such as a nursing home or assisted living facility. They assist with daily tasks and supervision to help the patient live as independently as possible and supplement other care they are receiving.



General caregiver duties

Whether formal or informal, caregiving duties include:

- Helping with activities of daily living (ADL), such as bathing and eating
- Running errands, such as grocery shopping
- Making financial and health decisions
- Doing housework and cooking
- · Driving the caregiving recipient to appointments
- Providing company and emotional support
- · Arranging medical care and other appointments and activities

Sixty-one percent of family caregivers work full time in addition to their caregiving responsibilities. Family caregivers often tap into vacation time to provide care, but they may lose wages, pensions or other benefits due to juggling caregiving and a career.

Interesting caregiver demographic statistics

Although men have started taking on more family caregiving in recent years, the AARP's caregiving report found that women still make up the majority of informal or family caregivers (61% vs. 39%). Female family caregivers are also more likely to experience caregiver stress, according to the Office on Women's Health, and they are more likely to have other health problems. Additionally, female family caregivers are less likely to get regular preventive screenings and often don't get enough sleep or regular physical activity.

Compared to people with conditions that do not require constant care and attention, family caregivers of people with Alzheimer's disease or dementia are more likely to have health problems or suffer from depression.

The AARP found that nearly 9 in 10 family caregivers of adults (89%) provide care for a relative, usually a parent or parent-in-law. However, 10% of caregivers provide care for a friend or neighbor. It's also becoming increasingly common for family caregivers to take care of someone who is of similar age. For example, 74% of family caregivers 75 or older provide care for someone in the same age range, according to the caregiving report.

What is caregiver stress?

Although caregiving can be very rewarding, it can also be extremely stressful. Family caregiver stress is caused by the emotional and physical strain of caregiving, according to the Office on Women's Health. Family caregivers may feel overwhelmed by the amount of care their loved one needs. They may feel like they are "on call" and do not have any free time.

Family caregivers can also experience stress because they see changes in their loved ones. For example, if the recipient has dementia or memory loss, they may no longer recognize the caregiver. They may also have behavioral changes or become too ill to follow requests. This can take a toll on the family caregiver because they remember how the person used to be. Family caregivers may also be in denial because they believe their loved one will get better.

Millennial family caregivers are more likely to experience stress-related conditions, according to a Blue Cross Blue Shield report. They are more likely to go to the ER or be hospitalized. Adjustment disorder and high blood pressure are also 82% more common among millennial family caregivers. Adjustment disorder includes stress, feelings of sadness or hopelessness and physical symptoms that can occur after a stressful life event.

Family caregiver stress can lead to burnout if left unchecked. Burnout is a state of emotional, mental and physical exhaustion. Those experiencing burnout may start to feel numb toward their loved one's needs or have an attitude change from positive to negative. In many instances, this lack of empathy can be referred to as "compassion fatigue."

While it's important to be aware of the emotional toll of family caregiving, the physical effects shouldn't be overlooked. Family caregiving can lead to a weakened immune system, excess weight or obesity or chronic conditions such as heart disease or arthritis. Family caregivers may also do a lot of lifting, bending and other actions that can wear on the body after a while.

It is extremely important for family caregivers to take care of themselves. It can be easy for them to dedicate all their time to caring for a loved one while neglecting their own health. According to the AARP report, 21% of caregivers said their health was fair or poor, up from 17% in 2015. Family caregivers who live with their care recipient also have poorer health than those who do not live with the person they are caring for.

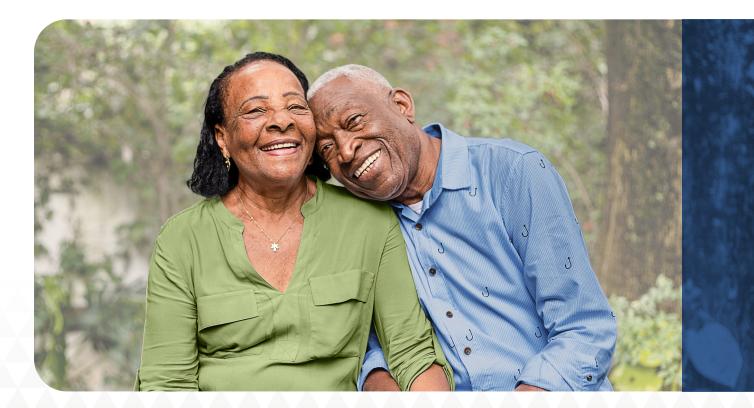
Signs of caregiver stress

Signs and symptoms of family caregiver stress include:

- Anger and frustration
- Feeling overwhelmed
- Feeling isolated
- Changes in sleeping habits (sleeping too much or too little)
- Weight changes (gaining or losing a lot of weight)
- Loss of interest in activities
- Constant feelings of sadness or worry
- Frequent headaches or body aches

Another sign of family caregiver stress is resentment. This can be toward the person receiving care or toward others who are not helping provide care. It is normal for family caregivers to feel some resentment, especially if the change is sudden. Caregiving can be disruptive to the family routine, forcing members to adjust quickly.

If the family caregiver starts to feel resentment, it is important they find a safe place to express their feelings. They may also want to seek professional help and support.



What causes caregiver burnout?

A number of different factors contribute to family caregiver stress and burnout. One of the major causes of family caregiver stress is the emotional demand that weighs on the caregiver. Depending on their condition, the recipient may need a lot of attention and care. Not only is this taxing emotionally, but it can take a toll physically as well. Family caregivers may not get enough sleep on a nightly basis. They may also be woken up in the middle of the night and find it hard to go back to sleep. This is extremely common—research has shown that up to 76% of family caregivers have poor sleep quality.

People caring for someone may also have responsibilities outside of caregiving, and those demands may conflict with each other. The majority of family caregivers are married, according to the AARP report, though less than one-third have a child or grandchild in their home. The family caregiver must balance the needs of their loved one, spouse and children, if they have them, in addition to caring for themselves. Not to mention balancing caregiving with the demands of a job if they are employed. This can be a lot for one person to handle.

Family caregivers may also feel isolated and lonely. They may feel like they don't have any support or they may not have time to spend with family and friends.

Fortunately, family caregiver burnout can be prevented. It is important for them to get help before caregiving becomes overwhelming. They may ask for help from other friends and family members and should accept help when it is offered. Many family caregivers feel like they need to do everything themselves. This doesn't have to be the case. They should try to be as specific as possible about what they need help with, such as grocery shopping, cooking, transportation or just a break. This lets others know where they can pitch in.

Financial strain

There is also a significant financial impact of family caregiving. The economic value of family caregivers' unpaid contributions was approximately \$600 billion in 2021. However, this number doesn't take into consideration out-of-pocket costs and lost wages.

Since they make up the majority of family caregivers, women bear the brunt of these costs and lost wages. The average costs for providing care to parents, parents-in-law and spouses (including unmarried partners) is \$43,000 over a lifetime.

Millennials also spend a larger portion of their incomes on caregiving than previous generations. They also earn less on average—one in three employed millennial family caregivers earns less than \$30,000 annually.

The majority of family caregivers (61%) were employed in the past year while caregiving, the AARP reports. Not only are they working their regular jobs, but they are also spending a significant amount of time caregiving.

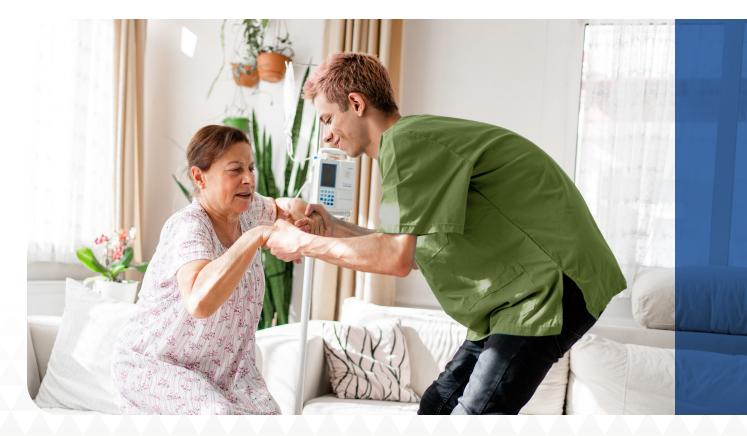
According to the AARP, 73% of family caregivers experienced changes related to their savings and 67% said they had changes to their debt. Forty percent of family caregivers said they experienced work changes, including getting a second job. The youngest family caregivers had the highest financial strain.

Unrealistic expectations

A lot is expected of family caregivers, from themselves and others. The feeling of having to do it all can add a lot of pressure. They may find themselves wondering if they are failing if they forget to do something or if they need to ask for help. This can lead to feelings of guilt or frustration.

One way a family caregiver can balance expectations is to write down a list of all the care tasks they perform. Then create another list of responsibilities outside of caregiving. They can then consider how important each of these tasks is and how they are prioritizing them. Are they doing more for their loved one than they are doing for themselves? Is there any way they can delegate some of the tasks?

It's also important for family caregivers to set boundaries if they feel they are taking on more than they can handle. It may help to think about whether the task is doable or not. How much time will it take up? Is there something else they could be doing with that time? It's OK to say no or take a step back in order to manage their stress.



Strategies for reducing *caregiver stress* **and** *burnout*

There are a number of effective strategies for reducing family caregiver stress. They can be used in tandem to create a supportive environment that allows the family caregiver to take care of themselves and their loved one. Below are a set of stress-relief solutions that providers can recommend to a family caregiver who needs help.

Finding community support



Whether it's online or in-person, caregivers may be able to find community support based on their loved one's specific illness or general support groups that welcome all types of caregivers. Finding a group of people who are also caregivers can help them realize they're not alone, give them a safe space to discuss their feelings and help them find new ways to cope with the challenges of family caregiving.

Reaching out to additional family members



Family caregivers should consider if there is anyone else in the family who can step in while the caregiver takes some time to themself and delegate certain tasks so they don't have to do them all on their own. They should have a discussion with other family members about the type of care the loved one needs now and will probably need in the future. It helps to think about each family member's strengths and how to put their skills to the best use.

Seeking financial support



The financial burden of family caregiving cannot be underestimated, so it's important for caregivers to be aware that they have options if the costs start to mount. Certain government programs, such as state Medicaid programs, and long-term care insurance policies may allow family members to become paid caregivers. Disease-specific organizations offer grants and financial assistance programs to people with that disease and their family caregivers. Family caregivers should be encouraged to look into programs their loved one might qualify for.

Home care assistance



Many family caregiver situations merit additional support through home care assistance. Home care agencies provide healthcare workers who come directly to families in need, lending medical expertise and close care tailored to the needs of patients. Physical therapists, for example, can help patients maintain functional abilities, including activities of daily living like bathing and dressing. Home care providers can also be a source of mental and emotional support for family caregivers.

Hospice care



If a caregiver's loved one has been diagnosed with six months or less to live, hospice may be an appropriate next step. Beyond physical and practical support, hospice providers can act as a sounding board for stressful feelings and offer suggestions for how to cope with the challenges of caregiving. They can also provide grief and bereavement support leading up to and after a loved one's death.

If not managed, caregiver stress can take a significant physical and emotional toll. Family caregivers often don't know where to go or how to ask for support, and caregiving is a task that can be too much for any one person to handle on their own. Whether it's asking for help from other family members, the community or seeking support from qualified healthcare professionals, caregivers have options for support. Be sure to encourage family caregivers to ask for help when they need it. It is one of the best things they can do for themselves and their loved one.



The Realities of Caregiver Stress

Sponsored by



To learn more, contact us at: info@stcroixhospice.com 855.278.2764 stcroixhospice.com