

## Update: Caregiving



### Caregiving in the U.S.

#### Challenges abound for caregivers, but support available

Family members who help seniors often don't view themselves as caregivers. But if you help care for a family member or friend who is unable to care for him- or herself, then you are a caregiver. And you're far from alone. According to the Administration on Aging, more than 44 million Americans provide care for an adult family member or friend; it will grow to more than 70 million in the next 25 years.

The goal of caregivers is to help seniors maintain a high level of independence, letting them feel self-reliant, understood, and respected, while also keeping them safe and well cared for.

Caregiving is a rewarding, yet demanding role. Often caregivers have no preparation, only heartfelt concern and a commitment to helping loved ones as they age. As the number of caregivers grows, so does the number of resources available to them. The National Family Caregivers Association offers a newsletter for family caregivers. Your local Area Agency on Aging may offer programs in caregiver skills or caregiver support groups. Many communities offer Meals on Wheels or adult day services, which can offer caregivers some respite. And numerous internet forums offer information, tips and support. See the Resources section for more information.

One of the greatest obstacles facing family caregivers is that 60% of them are employed full time, so they face the challenge of balancing family, caregiving, and work. Caregiving is rapidly becoming a concern for businesses as well, with \$34 billion in lost productivity each year. Absenteeism, distractions, arriving late and leaving early can all occur when employees find themselves caring for aging loved ones. Even caring long-distance can be difficult and expensive when you can't observe first-hand what's happening with an aging relative and have to travel to stay involved.

About one-third of large employers offer an eldercare benefit to employees, but many of these programs are limited. Other companies offer formal and informal support through flexible work schedules, caregiver support groups, informational seminars or health fairs, Employee Assistance Programs that include caregiver support, or subsidized emergency support for full-time caregivers. Often, however, employees make time for caregiving themselves by using vacation or sick days or the Family and Medical Leave Act (FMLA).

Another concern is the toll caregiving takes on those who do it. The National Institutes of Health (NIH) has found that family caregiving can shorten caregivers' lives by 10 years.

This means it is especially important for caregivers to take care of their own needs. Have a plan for your health and well-being as well as that of your loved one. You can't effectively care for someone else if you don't take care of yourself first. See "10 tips for family caregivers" for ways to do this.

It is particularly important to monitor yourself for signs of depression. Depression is common among family caregivers – they experience it at a rate twice that of non-caregivers. Address your needs, ask for help, and find sources of emotional support. Tend to your physical needs – eat right, exercise and get enough rest. Do things that make you happy and healthy, and in turn you'll be happier caring for your loved one.

Despite the challenges, caregiving can be extremely fulfilling. A Caring Today magazine survey found that 80% of caregivers find caregiving emotionally rewarding, despite some initial negative perceptions.

#### Resources

As concerns and needs have grown, so too have the resources to support caregivers. Here are a few leading resources:

Family Caregivers Alliance

[www.caregiver.org](http://www.caregiver.org)

National Family Caregivers Association

[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

And Thou Shalt Honor

[www.andthoushalthonor.org](http://www.andthoushalthonor.org)

Family Caregiving 101

[www.familycaregiving101.org](http://www.familycaregiving101.org)

National Caregiver's Library

[www.caregiverslibrary.org](http://www.caregiverslibrary.org)

National Association of Area Agencies on Aging

[www.n4a.org](http://www.n4a.org)

#### About My Health Care Manager

My Health Care Manager helps older adults and their families understand and navigate the health issues and complex decisions associated with aging. For more information, contact My Health Care Manager, 8520 Allison Pointe Blvd., Suite 230, Indianapolis, IN 46250, 317-598-8921 or 800-499-8020 or visit us on the Web at [www.MyHealthCareManager.com](http://www.MyHealthCareManager.com).

## Complex conversations -

### A New Perspective for Caregivers

Having conversations about planning for an older adult's senior years presents a daunting challenge for families. The reversing roles of parent and child can create a different and difficult dynamic. Planning ahead for these conversations can allow for an honest exchange of feelings and fears, and reduce anxiety about issues such as health care, finances, or when is it time to stop driving or living independently.

"Communications should begin with a sense of trust and respect," says Anita Siccardi, EdD, APRN, BC, director of the University of Indianapolis' Graduate Nursing Program and director of Professional Services for My Health Care Manager. "If an older adult can share his or her desires and plans with family members, then everyone can 'be on the same page,' and avoid making decisions in the heat of a crisis, when emotions run high."

These complex conversations don't have to be difficult. Begin by calling a family meeting – in person if you can, or by phone or over the Internet. If you're not comfortable running a family meeting, consider engaging a counselor, trusted advisor, geriatric care manager, or clergyman.

- Choose topics to discuss in advance, and recognize that tackling everything at once is not possible.
- Take notes rather than relying on individuals' recollection or interpretation.
- Speak with care and empathy, be supportive, curious, and helpful in solving problems, and you'll see better results. A successful outcome depends not just on what you say, but how you say it.
- Be open to sharing everyone's wants and needs. Listen with your eyes and heart, as well as your ears.
- Don't hide information. Be open and clear about the facts.
- Don't assume that others see things from your point of view. And don't take verbal attacks personally – this is a tense situation for everyone.
- Be prepared to discuss a variety of options and their advantages and disadvantages.
- Ask questions to clarify issues and give the senior the chance to draw conclusions and make choices between the various options.
- End the discussion before everyone becomes tired, overwhelmed, or frustrated. Agree to continue the discussion if you don't reach closure.

### 10 tips for family caregivers

Caregiving is a generous and loving responsibility, but it can also be time-consuming and draining. The National Family Caregivers Association offers these important suggestions for those caring for aging loved ones:

1. Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.
2. Watch out for signs of depression, and don't delay in getting professional help when you need it.
3. When people offer to help, accept the offer and suggest specific things that they can do.
4. Educate yourself about your loved one's condition and how to communicate effectively with their doctors.
5. Be open to technologies and ideas that promote your loved one's independence.
6. Trust your instincts. Most of the time, they'll lead you in the right direction.
7. Caregivers often do a lot of lifting, pushing, and pulling. Be good to your back.
8. Grieve for your losses, and then allow yourself to dream new dreams.
9. Seek support from other caregivers. There is great strength in knowing you are not alone.
10. Stand up for your rights as a caregiver and a citizen.

### A My Health Care Manager real life story 'I feel like I have my life back'

At age 52, Ann Miller became the primary caregiver for her 82-year-old mother, Ruth. Married with three grown children, Ann became exhausted trying to meet Ruth's needs while caring for her own family and pursuing her career. She often felt torn between her roles as daughter, wife, mother and businesswoman, and felt that she was letting everyone down. She became anxious and depressed.

Ann's reaction was not unusual. Families are often overwhelmed by the magnitude of the challenges and tasks required in caregiving. "I was there as much as possible. I didn't know what else to do" said Ann. "But often when I visited Mom, she had the same clothes on, didn't smell as if she had showered, and didn't look like she had used her toothpaste,"

This is where My Health Care Manager came in. A personally assigned Health Care Manager completed an assessment to understand the family's situation, needs and goals, and then created a plan. In Ann's case, her Health Care Manager developed a schedule of support needs to give structure to each day. It could be followed by anyone: Ann, a neighbor, her grown children, or a hired companion. With the structure in place, Ruth's days ran more smoothly.

Ann also followed a recommendation to hire a companion to stay with Ruth for several hours on select days each week. This provided Ann much-needed time to resume her normal activities without feeling stressed or guilty, as she knew her mother was safe, happy, and receiving good care.

"With My Health Care Manager in the loop, I feel like I have my life back," commented Ann. "Mother is happier and getting the support she needs. So while I am still a caregiver, it's not 24/7, and I get to spend quality time with Mother without always being exhausted."

This information is meant to complement the advice of your health care providers, not replace it. Talk to your doctor if you have any health concerns.

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