How to Be a Caregiver

By Tara Parker-Pope

Even if you're not a caregiver now, odds are that you will find yourself in the role someday. In the United States <u>about one in five adults</u> is providing unpaid health or supportive care to someone they love — an aging parent, a family member or child with a disability or a spouse, partner or friend with an illness. We asked experts on caregiving and aging, as well as dozens of people who have been caregivers themselves, for their best advice to help the next generation of caregivers.

Six Things to Know About Caregiving

We asked readers who had cared for a loved one what a new caregiver should know. Here are six strategies to guide you.



Rosalynn Carter, the former first lady who started the <u>Rosalynn Carter Institute for Caregiving</u>, famously stated that there are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will become caregivers and those who will *need* caregivers.

Sometimes a person becomes a caregiver overnight after a health crisis, like a stroke or cancer diagnosis. But often, caregiving starts slowly with a few errands like picking up groceries. While you may not call yourself a caregiver, at some point it becomes clear that life has changed and you don't have the freedom to go on vacation or out with friends unless someone else can step into your caregiving role.

"If we acknowledge that we're caregivers, we're much more apt to get resources, support and services that can help us in that role and help the loved ones we're caring for," said Amy Goyer, author of "Juggling Life, Work and Caregiving," and a caregiving expert for AARP, the advocacy group for older people. "Personally it's important to acknowledge it. It's something to plan for and schedule in your life."

When I asked readers who had cared for a loved one to tell me what we should know about caregiving, I received hundreds of emails from current and former caregivers who wanted to help. What was most notable is how consistently caregivers talked about the joy and satisfaction of the work they do, despite the enormous hardship it sometimes imposed. A reader named Marnie shared her memories of caring for her mother.

"The early days of taking care of Mom weren't easy. It's always difficult having to live with someone else, and I know she felt it too. But we shared our feelings and worked things out. My favorite memory is of Mom and me sitting on our wonderful screened-in porch, listening to the Sinatra station while Mom rocked in her chair, and I worked on my needlepoint. We would spend hours on that porch. Mom has been gone for four years now. If I could spend just a few more hours with her on that screened-in porch, rocking and needlepointing, I'd be in heaven."

Caregiving requires an enormous commitment of time and energy, and most of this guide focuses on practical advice for getting organized and finding resources to ease the burden. But experienced caregivers also offer six personal strategies to guide you through the challenging times.

- **1. Let the patient lead.** Readers consistently talked about the importance of autonomy for the one receiving care. Include the person in care decisions whenever possible. Make sure doctors don't talk as if the patient isn't in the room.
- **2. Focus on comfort.** Let comfort, joy and pleasure be your guideposts. Try not to nag. Readers talked about the importance of small moments of shared joy listening to swing music or a favorite crooner, playing card games and going for ice cream.
- **3. Listen to the experts.** Find experts to advise you, and listen to them. Arm yourself with information from caregiving organizations and support groups. Trust your instincts. Ignore most of the unsolicited advice you are likely to receive.
- **4.** Talk to other caregivers. Support groups will be one of your best resources.
- **5. Take care of yourself**. Even five- and 10-minute breaks during the day can help. Try keeping a <u>gratitude journal</u>, download a meditation app or do a six-minute workout to refresh your mind and body. Use adult day care or in-home caregivers from time to time so you can take a break. Take up friends on their offers to help, even if it's just to get your hair done. Exercising, sleeping and eating well will make you a better caregiver for your loved one.
- **6. Shed the guilt.** Guilt is a common theme here, but experienced caregivers say it's important to know your limits, <u>practice self-compassion</u>, ask for help and remind yourself that the work you're doing is difficult and important.

Is Giving or Receiving Care in Your Future?

If caregiving is not a topic you've thought about, it's time to start. A number of global and social trends have changed the outlook for all of us, whether it's giving care or needing it. Rising health care costs mean more people will require care at home with a family member because they can't afford to pay for it. The aging population will force more adult children, spouses, relatives and friends into caregiving roles. Demographic changes in child rearing have shifted the care giving burden to a younger population. Couples have delayed having children and families have gotten smaller, and now people in their 20s and 30s are shouldering the

burdens of caregiving at the expense of their careers, and they have fewer siblings to share the load.

Today, 21.3 percent of U.S. adults are caregivers, according to <u>Caregiving in the U.S. 2020</u>, a report from the National Alliance for Caregiving and AARP. The report defines a caregiver as someone who has provided care to an adult or a child with special needs at some time in the past 12 months. The number of caregivers is growing, and now totals about 53 million adults, up 20 percent from 43.5 million caregivers in 2015. Here are some facts about caregivers in the United States

- Most caregivers (about 90 percent) take care of a relative, usually a parent or spouse, while 10 percent care for a friend or neighbor.
- Women are more likely to be caregivers than men, and make up about 60 percent of unpaid caregivers.
- While most caregivers of adults take care of just one person, nearly one in four (24 percent) takes care of two or more people, up from 18 percent in 2015.
- More young people are taking on caregiving roles. About a third of caregivers are 39 or younger, and 6 percent of them are from Generation Z age 23 or younger.
- Caregiving is time consuming. On average, today's caregivers provide about 24 hours of care each week. And most of them (61 percent) have another job.
- Caregiving takes a toll on health. More Americans (23 percent) say caregiving has made their own health worse, up from 17 percent in 2015.

The global pandemic, which has taken a disproportionate toll on people who live in nursing homes and assisted care facilities, is also expected to change how we care for people as they age or become ill. About 40 percent of deaths in the United States from Covid-19 are linked to nursing homes, prompting speculation that caregiving will continue to shift away from group settings and into the home.

"We know many people, because of the pandemic, are re-examining plans," Ms. Goyer said. "People are less excited about going to live in a nursing facility or assisted living facility because of Covid-19."

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