

Tips for Alzheimer's and Dementia Caregivers

Dealing with a diagnosis of dementia or Alzheimer's in your family? This guide will help you prepare for the caregiving road ahead and get the help you need.



The Alzheimer's and dementia care journey

Caring for someone with Alzheimer's disease or another type of dementia can be a long, stressful, and intensely emotional journey. But you're not alone.

In the United States, there are more than 16 million people caring for someone with dementia—and many millions more around the world. As there is currently no cure for Alzheimer's or dementia—and only limited medical treatments available for the symptoms—it is your caregiving that can make the biggest difference to your loved one's quality of life. That is a remarkable gift.

However, caregiving can also become all-consuming. As your loved one's cognitive, physical, and functional abilities diminish over a period of years, it's easy to become overwhelmed and neglect your own health and well-being. The burden of caregiving can put you at increased risk for significant health problems and many dementia caregivers experience depression, high levels of stress, or burnout. And nearly all Alzheimer's or

dementia caregivers at some time experience sadness, anxiety, loneliness, and exhaustion. Seeking help and support along the way is not a luxury; it's a necessity.

Just as each individual with Alzheimer's disease progresses differently, so too can the caregiving experience vary widely from person to person. However, there are strategies that can aid you as a caregiver and help make your caregiving journey as rewarding as it is challenging.

The challenges and rewards of Alzheimer's care

Caring for a person with Alzheimer's disease or dementia can often seem to be a series of grief experiences as you watch your loved one's memories disappear and skills erode. The person with dementia will change and behave in different, sometimes disturbing or upsetting ways. For both caretakers and their patients, these changes can produce an emotional wallop of confusion, anger, and sadness.

As the disease advances, your loved one's needs will increase and your caregiving responsibilities will become more challenging. At the same time, the ability of your loved one to show appreciation for all your hard work will diminish. Caregiving can literally seem like a thankless task. For many, though, a caregiver's journey includes not only challenges, but also many rich, life-affirming rewards.

Challenges of Alzheimer's and dementia care

- Overwhelming emotions as your loved one's capabilities decrease.
- Fatigue and exhaustion.
- Isolation and loneliness.
- Financial and work complications.

Rewards of Alzheimer's and dementia care

- Your bond with the patient deepens through care, companionship, and service.
- Your problem-solving and relationship skills improve.
- You form new relationships through support groups.
- Unexpected rewards develop through compassion and acceptance.

Tip 1: Prepare for the road ahead

The more you learn about your loved one's disease and how it will progress over the years, the better you'll be able to prepare for future challenges, reduce your frustration, and foster reasonable expectations. In the early stages of Alzheimer's, for example, you can support your loved one's independence and self-care, but their cognitive and physical regression means they will ultimately require 24-hour care.

[Read: Coping with an Alzheimer's or Dementia Diagnosis]

Though it may be hard to contemplate such a difficult outlook, the sooner you put plans in place, the more your loved one can be involved in the decision-making process. Paying for long-term care can be a major source of stress, so it's important to research all your options as early as possible. Consult with the patient's medical team and other family members to make legal and financial arrangements and determine the long-term care options that are best suited to you and your loved one.

Questions to consider in preparing for Alzheimer's and dementia care:

- **Who will make healthcare and/or financial decisions when the person is no longer able to do so?** While a difficult topic to bring up, if your loved one is still lucid enough, getting their wishes down on paper means they'll be preserved and respected by all members of the family. You'll want to consider power of attorney, both for finances and for healthcare. If the person has already lost capacity, you may need to apply for guardianship/ conservatorship.
- **How will care needs be met?** Sometimes family members assume that a spouse or nearest family member can take on caregiving, but that's not always the case. Caregiving is a major commitment that gets bigger over time. Family members may have their own health issues, jobs, and responsibilities. Communication is essential to make sure that the needs of the Alzheimer's patient are met, and that the caregiver has the support to meet those needs.
- **Where will your loved one live?** Is their own home appropriate, or is it difficult to make safe for later? If your loved one currently lives alone or far from any family or other support, it may be necessary to relocate or consider a facility with more support.

Tip 2: Develop a personal support plan

Balancing the enormous task of caring for a cognitively-impaired adult with your other responsibilities requires skill, attention, and meticulous planning. By focusing so diligently on your loved one's needs, it's easy to fall into the trap of neglecting your own welfare. If you're not getting the physical and emotional support you need, you won't be able to provide the best level of care, and you face becoming overwhelmed.

Ask for help. You cannot do it all alone. It's important to reach out to other family members, friends, or volunteer organizations to help with the daily burden of caregiving. Accepting help for mundane tasks such as grocery shopping and cleaning can free you up to spend more quality time with the patient. Schedule frequent breaks throughout the day to pursue hobbies and interests and stay on top of your own health needs. You're not being neglectful or disloyal to your loved one. Caregivers who take regular time away not only provide better care, they also find more satisfaction in their caretaking roles.

Learn or update caregiving skills. Being thrust into the role of caregiver doesn't come with an instruction manual, but there are books, workshops, and online training resources that can teach caregiving skills. As the disease progresses and challenges change, you'll need to update your skillset and find new ways of coping.

Join a support group. You'll be able to learn from the experiences of others who have faced the same challenges. Connecting with others who know first-hand what you're going through can also help reduce feelings of isolation, fear, and hopelessness.

Make use of available resources. There are a wealth of community and online resources to help you prioritize your efforts and provide effective care. Start by finding the Alzheimer's Association in your country. These organizations offer practical support, helplines, advice, and training for caregivers and their families. They can also put you in touch with local support groups.

Plan for your own care. Visit your doctor for regular checkups and pay attention to the signs and symptoms of excessive stress. It's easy to abandon the people and activities you love when you're mired in caregiving, but you risk your health and peace of mind by doing so. Take time away from caregiving to maintain friendships, social contacts, and professional networks, and pursue the hobbies and interests that bring you joy.

Get moving. Regular exercise not only keeps you fit, it releases endorphins that can really boost your mood. Aim for at least 30 minutes of exercise on most days. If it's difficult to get away for that long at once, break the time up into 10 minute sessions sprinkled throughout the day.

Talk to someone. Talk to a trusted friend, family member, clergy member, or therapist, about what you're going through. The simple act of talking face-to-face with someone who cares can be extremely cathartic—and a great stress reliever.

Practice a relaxation technique. Caregiving for a loved one with dementia can be one of the most stressful tasks you'll undertake in life. To combat this stress and boost your mood and energy levels, you need to activate your body's natural relaxation response. As well as exercising and connecting face-to-face with others, try relaxation techniques such as deep breathing, meditation, or yoga.

Sources of caregiver support

In-home help refers to caregivers that you can hire to provide assistance for your loved one. In-home help ranges from a few hours a week of assistance to live-in help, depending on your needs. You'll want to evaluate what sort of tasks you'd like help with, how much you can afford to spend, and what hours you need. Getting help with basic tasks like housekeeping, shopping, or other errands can also help you provide more focused care for your loved one.

Day programs, also called adult day care, offer a variety of activities and socialization opportunities. Adult day care services also provide the chance for you as the caregiver to continue working or attend to other needs. There are some programs that specialize in dementia care.

Respite care gives you a block of time as a caregiver to rest, travel, or attend to other things. Enlist friends and family who live near you to run errands, bring a hot meal, or watch the patient so you can take a well-deserved break. Volunteers or paid help can also provide in-home respite services, either occasionally or on a regular basis. Or you can explore out-of-home respite programs such as adult day care centers and nursing homes.

Tip 3: Cope with changes in communication

As your loved one's Alzheimer's or dementia progresses, you'll notice changes in communication. Trouble finding words, increased hand gestures, easy confusion, even inappropriate outbursts are all normal. Here are some do's and don'ts on communicating with your loved one:

Communication Do's and Don'ts

DO . . .

Avoid becoming frustrated by empathizing and remembering your loved one can't help their condition. Making them feel safe rather than stressed will make communication easier. Take a short break if you feel your fuse getting short.

Keep communication short, simple, and clear. Give one direction or ask one question at a time.

Tell your loved one who you are if there appears to be any doubt.

Call your loved one by name.

Speak slowly. Your loved one may take longer to process what's being said.

Use closed-ended questions which can be answered "yes" or "no." For example, ask, "Did you enjoy the food at dinner?" instead of "What did you have for dinner?"

Find a different way to say the same thing if it wasn't understood. Try a simpler statement with fewer words.

Use distraction or fib if telling the whole truth will upset the person with dementia. For example, to answer the question, "Where is my mother?" it may be better to say, "She's not here right now" instead of "She died 20 years ago."

Communication Do's and Don'ts

Use repetition as much as necessary. Be prepared to say the same things over and over as the person can recall them for more than a few minutes at a time.

Use techniques to attract and maintain your loved one's attention. Smile, make eye contact, use gestures, touch, and other body language.

DON'T . . .

Ever say things like: “Do you remember?” “Try to remember!” “Did you forget?” “How could you not know that?!”

Ask questions that challenge short-term memory such as “Do you remember what we did last night?” The answer will likely be “no,” which may be humiliating for the person with dementia.

Talk in paragraphs. Instead, offer one idea at a time.

Point out the person's memory difficulty. Avoid remarks such as “I just told you that.” Instead, just repeat over and over.

Talk in front of the person as if they weren't present. Always include them in any conversation when they are physically present.

Use lots of pronouns such as “there, that, those, him, her, it.” Use nouns instead. For example, instead of “sit there,” say: “sit in the blue chair.”

Use slang or unfamiliar words. The person may not understand the latest terms or phrases.

Use patronizing language or “baby talk.” A person with dementia will feel angry or hurt at being talked down to.

Use sarcasm or irony, even if meant humorously. Again, it can cause hurt or confusion.

Tip 4: Develop day-to-day routines

Having a general daily routine in Alzheimer's and dementia care helps caregiving run smoothly. These routines won't be set in stone, but they can give a sense of consistency, which is beneficial to the patient even if they can't communicate it.

Keep a sense of structure and familiarity. Try to keep consistent daily times for activities such as waking up, mealtimes, bathing, dressing, receiving visitors, and bedtime. Keeping these things at the same time and place can help orientate the person with dementia.

Let your loved one know what to expect even if you are not sure that they completely understand. You can use cues to establish the different times of day. For example, in the morning you can open the curtains to let sunlight in. In the evening, you can put on quiet music to indicate it's bedtime.

Involve your loved one in daily activities as much as they're able. For example, they may not be able to tie their shoes, but may be able to put clothes in the hamper. Clipping plants in the yard may not be safe, but they may be able to weed, plant, or water.

Planning activities

As you develop daily routines, it's important to include activities and visitors. You want to make sure that the Alzheimer's patient is getting sensory experiences and socialization, but not to the point of getting overstimulated and stressed. Here are some suggestions for activities:

Start with the person's interests. Ask family and friends about interests your loved one used to have. You'll want to tailor the interests to their current level of ability so they don't get frustrated.

Vary activities to stimulate different senses—sight, smell, hearing, and touch—and movement. For example, you can try singing songs, telling stories, dancing, walking, or tactile activities such as painting, gardening, or playing with pets.

Planning time outdoors can be very therapeutic. You can go for a drive, visit a park, or take a short walk. Even sitting on a balcony or in the backyard can be relaxing.

Consider outside group activities designed for those with Alzheimer's or dementia. Senior centers, community centers, or adult day care programs may host these types of activities.

Visitors and social events

Visitors can be a rich part of the day for someone with dementia. It can also provide an opportunity for you as the caregiver to socialize or take a break.

- Plan visitors at a time of day when your loved one can best handle them.
- Offer visitors communication tips if they seem uncertain; suggest they bring memorabilia your loved one may like, such as favorite music or books.
- For family and social events, focus on events that won't overwhelm your loved one; excessive activity or stimulation at the wrong time of day may be too much to handle.

Tip 5: Deal with problem behaviors

One of the major challenges of caring for a loved one with Alzheimer's or another dementia is coping with the troubling behavior and personality changes that often occur. These behaviors include aggressiveness, wandering, hallucinations, and eating or sleeping difficulties that can be distressing to witness and make your role as caregiver even more difficult.

Often, these behavioral issues are triggered or exacerbated by your loved one's inability to deal with stress, their frustrated attempts to communicate, or their environment. By making some simple changes, you can help ease your loved one's stress and improve their well-being, along with your own caregiving experience.

Tip 6: Make time for reflection to help with acceptance

One of the biggest challenges as a caretaker for someone with dementia is to accept what is happening to your loved one. At each new stage of the disease, you have to alter your expectations about what your loved one is capable of. By accepting each new reality and taking time to reflect on these changes, you can better cope with the emotional loss, and deepen the feelings of satisfaction in your caregiving role.

Keep a daily journal to record and reflect on your experiences. By writing down your thoughts, you can mourn losses, celebrate successes, and look for those thought patterns that keep you from acting in the present.

Count your blessings. A daily gratitude list can chase away the blues and let you focus on what your loved one is still capable of, rather than the abilities they've lost.

Celebrate what is possible. Your loved one still has many abilities. Structure activities to invite participation on whatever level is possible, and you will both find enjoyment.

Try to envision your loved one's world. Imagine not being able to remember and do life's simple tasks. By valuing what your loved one is able to give, you can find satisfaction on even the toughest days.

Improve emotional awareness. Remaining engaged, focused, and calm in the midst of such tremendous responsibility can challenge even the most capable caregivers. By developing your emotional awareness skills, however, you can relieve stress, experience positive emotions, and bring new peace and clarity to your caretaking role.

The rewards of connecting

Even when your loved one can no longer verbally express love or appreciation, you can find a sense of reward in your caregiving role by making time each day to really connect with the person. Avoid all distractions and focus fully on your loved one. Make eye contact (if that's possible), hold their hand or stroke their cheek, and talk in a calm, reassuring tone of voice. When you connect in this way, you'll experience a process that boosts your mood, reduces stress, and supports your physical and emotional well-being. And it can also have the same effect on your loved one.

How to help a dementia caregiver

If a friend or family member is caring for someone with Alzheimer's or dementia, it's important to offer all the help and support you can.

Don't wait to be asked to help. Many caregivers find it difficult to ask others for help, no matter how much they may need it, so make the offer. And when you do, be specific. Make suggestions like, "I'm free tomorrow afternoon, can I sit with the patient while you

take a break?” or “What can I get you from the grocery store today?” Helping out with even the most mundane chores can free the caregiver up to spend more quality time with the patient or take a break to recharge their batteries.

Be a friend. Caregivers are prone to withdrawing from family and friends but they still need regular contact with the outside world. Phone calls, texts, or emails are fine, but nothing beats a personal visit to lift a caregiver’s mood. Again, don’t wait to be asked; be the one to reach out.

Be a good listener. Venting frustrations about caregiving can be a great stress reliever. Listen to the caregiver’s fears and concerns without judging.

Show your gratitude. If the caregiver is a sibling looking after your parent, for example, it’s important to express your gratitude. The patient with mid- or late-stage Alzheimer’s may not be able to so it’s important other family members recognize the caregiver’s hard work and sacrifice. While a card or a simple “Thank you” can go a long way, when accompanied by the offer of some respite, it can be a blessing.

Recognize the signs of caregiver stress and encourage the caregiver to focus more on their own health and well-being.

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