Alzheimer’s and Dementia Care: Help for Family Caregivers

Caring for someone with Alzheimer’s disease or dementia? This guide will help you cope with the challenges at each stage, find the support you need, and reap the rewards of caregiving.

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, it is often your caregiving and support that makes 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 gradually diminish over time, it’s easy to become overwhelmed, disheartened, 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 even 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 or dementia 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.

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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 caregivers and their patients, these changes can produce an emotional wallop of confusion, frustration, and sadness.

As the disease advances through the different stages, your loved one’s needs increase, your caregiving and financial responsibilities become more challenging, and the fatigue, stress, and isolation can become overwhelming. At the same time, the ability of your loved one to show appreciation for all your hard work only diminishes. Caregiving can literally seem like a thankless task.

[Read: Family Caregiving]

For many, though, a caregiver’s journey includes not only huge challenges, but also many rich, life-affirming rewards.

**Caregiving is a pure expression of love.** Caring for a person with Alzheimer’s or dementia connects you on a deeper level. If you were already close, it can bring you closer. If you weren’t close before, it can help you resolve differences, find forgiveness, and build new, warmer memories with your family member.

**It changes your perspective on life.** The act of caregiving can help you appreciate your own life more. Many people find that their priorities change afterwards. The trivial, day-to-day worries that once seemed so important seem to fade away and they’re able to focus on the things that are really meaningful in life.

**Provides purpose.** Caring for someone with Alzheimer’s or dementia makes you feel needed and valued. It can also add structure and meaning to your life. Each day you’re making a huge difference in someone’s life, even if they’re no longer able to acknowledge it or express their gratitude.

**Adds a sense of accomplishment.** Learning new skills and coping techniques can boost your confidence and overcoming new challenges can improve your problem-solving skills. Attending support groups can also broaden your social network and help you form new, rewarding relationships.

**Caregiving can teach younger family members** the importance of caring, compassion, and acceptance. Caregiving for someone with dementia is such a selfless act. Despite the stress, demands, and heartache, it can bring out the best in us to serve as role models for
our children.

**Caregiving in the early stages of Alzheimer’s or dementia**

In the [early stages of Alzheimer’s disease](#) or another type of dementia, your loved one may not need much caregiving assistance. Rather, your role initially may be to help them come to terms with their diagnosis, plan for the future, and stay as active, healthy, and engaged as possible.

**Accept the diagnosis.** Accepting a dementia diagnosis can be just as difficult for family members as it for the patient. Allow yourself and your loved one time to process the news, transition to the new situation, and grieve your losses. But don’t let denial prevent you from seeking early intervention.  

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

**Deal with conflicting emotions.** Feelings of anger, frustration, disbelief, grief, denial, and fear are common in the early stages of Alzheimer’s or dementia—for both the patient and you, the caregiver. Let your loved one express what they’re feeling and encourage them to continue pursuing activities that add meaning and purpose to their life. To deal with your own fears, doubts, and sadness, find others you can confide in.

**Make use of available resources.** There are a wealth of community and online resources to help you provide effective care on this journey. Start by finding the Alzheimer’s Association in your country (see links below). 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.

**Learn all you can about your loved one’s dementia.** While everyone’s experiences of Alzheimer’s or dementia are different, the more you learn about the condition and how it’s likely to progress, the better you’ll be able to prepare for future challenges, reduce your frustration, and foster reasonable expectations. There are also books, workshops, and online training resources that can teach caregiving skills.

**Prepare for the road ahead.** With your support, your loved one may be able to maintain their independence and live alone in the early stages of dementia. However, their cognitive and physical regression means they will ultimately require around-the-clock help. Putting
plans for their future housing and care in place now can help reduce stress in the future, enable your loved one to be involved in the decision-making process, and ensure their legal, financial, and healthcare wishes are respected.

**Preserving your loved one’s independence**

**Take steps to slow the progression of symptoms.** While treatments are available for some symptoms, lifestyle changes can also be effective weapons in slowing down the disease’s progression. Exercising, eating and sleeping well, managing stress, and staying mentally and socially active are among the steps that can improve brain health and slow the process of deterioration. Making healthy lifestyle changes alongside your loved one can also help protect your own health and counter the stress of caregiving.

[Read: Preventing Alzheimer’s Disease and Dementia—or Slowing its Progress]

**Help with short-term memory loss.** In the early stages, your loved one may need prompts or reminders to help them remember appointments, recall words or names, keep track of medications, or manage bills and money, for example. To help your loved one maintain their independence, instead of simply taking over every task yourself, try to work together as a partnership. Let your loved one indicate when they want help remembering a word, for example, or agree to check their calculations before paying bills. Encourage them to use a notebook or smartphone to create reminders to keep on hand.

**Caregiving in the middle stages of Alzheimer’s or dementia**

As your loved one’s Alzheimer’s disease or dementia symptoms progress, they’ll require more and more care—and you’ll need more and more support as their caregiver. Your loved one will gradually experience more extensive memory loss, may become lost in familiar settings, no longer be able to drive, and fail to recognize friends and family. Their confusion and rambling speech can make communicating more of a challenge and they may experience disturbing mood and behavior changes along with sleep problems.

You’ll need to take on more responsibilities as your loved one loses independence, provide more assistance with the activities of daily living, and find ways of coping with each new challenge. Balancing these tasks with your other responsibilities requires attention, planning, and lots of support.
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. Schedule frequent breaks throughout the day to pursue your hobbies and interests and stay on top of your own health needs. This is 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.

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.

Sources of caregiver support

In-home help ranges from a few hours a week of caregiving assistance to live-in help, depending on your needs and what you can afford. You can also hire help for basic tasks like housekeeping, shopping, or other errands to free you up to provide more focused care for your loved one.

Adult day care offers activities and socialization opportunities for your loved one and the chance for you to continue working or attend to other needs. Look for adult day care 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. Or you can explore out-of-home respite programs such as adult day care centers and nursing homes.

Make time for reflection

At each new stage of dementia, 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 find greater 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 challenge negative thought patterns that impact your mood and outlook.
Count your blessings. It may sound counterintuitive in the midst of such challenges, but keeping a daily gratitude list can help chase away the blues. It can also help you focus on what your loved one is still capable of, rather than the abilities they’ve lost.

Value what is possible. In the middle stages of dementia, your loved one still has many abilities. Structure activities to invite their participation on whatever level is possible. By valuing what your loved one is able to give, you can find pleasure and satisfaction on even the toughest days.

[Read: Surviving Tough Times by Building Resilience]

Improve your 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.

Develop helpful daily routines

Having general daily routines and activities can provide a sense of consistency for an Alzheimer’s or dementia patient and help ease the demands of caregiving. Of course, as your loved one’s ability to handle tasks deteriorates, you’ll need to update and revise these routines.

Keep a sense of structure and familiarity. Try to keep consistent daily times for activities such as waking up, mealtimes, dressing, receiving visitors, and bedtime. Keeping these things at the same time and place can help orientate the person with dementia. Use cues to establish the different times of day—opening the curtains in the morning, for example, or playing soothing music at night to indicate 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.

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.

Spare time outdoors. Going for a drive, visiting a park, or taking a short walk can be very therapeutic. Even just sitting outside can be relaxing.
Find group activities designed specifically for those with Alzheimer’s or dementia. Senior centers, community centers, or adult day care programs often host these types of activities.

Plan visitors and social events at times when your loved one can best handle them. Excessive activity or stimulation at the wrong time of day may be too much to handle. Offer communication tips if visitors seem uncertain or suggest they bring memorabilia your loved one may like, such as favorite books or music.

Cope with changes in communication

As your loved one’s Alzheimer’s or dementia progresses, you’ll notice changes in how they communicate. They may have trouble finding words, substitute one word for another, repeat the same things over and over, or become easily confused. Increased hand gestures, losing their train of thought, and even inappropriate outbursts are all common as well.

Even if your loved one has trouble maintaining a conversation—or less interest in starting one—it’s important to encourage social interaction. Making them feel safe rather than stressed will make communication easier, so try to manage your own frustration levels.

Be patient. If your loved one has difficulty recalling a word, for example, allow them time. Getting anxious or impatient will only inhibit their recall. Gently supply the word or tell the person that you can come back to it later.

Be aware of your body language. Your loved one responds to your facial expression, tone of voice, and nonverbal cues as much as the words you choose. Make eye contact, stay calm, and keep a relaxed, open posture.

Speak slowly and clearly. Give one direction or ask one question at a time, use short sentences, and give your loved one more time to process what’s being said. Find a simpler way to say the same thing if it wasn’t understood the first time.

Avoid questions that challenge short-term memory, such as “Do you remember what we did last night?” The answer will likely be “no,” which can be humiliating for someone with Alzheimer’s or dementia.

Maintain respect. Don’t use patronizing language, “baby talk”, or sarcasm. It can cause hurt or confusion.

Take a short break if you feel your fuse getting short. Try using quick stress relief to calm
down and regain your balance.

Do’s and Don’ts for Talking to Someone with Dementia

DO . . .

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

Listen attentively. Avoid distractions such as the TV or your cell phone and focus your attention on your loved one.

Use distraction or fib if telling the whole truth will upset the person. 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.”

Use repetition as much as necessary. Be prepared to say the same things over and over as the person can’t recall them for more than a few minutes at a time.

DON’T . . .

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

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

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, him, it.” Use nouns instead. For example, instead of “Sit there,” say: “Sit in the blue chair.”

Coping with changes in behavior and personality

As well as changes in communication during the middle stages of dementia, troubling behavior and personality changes can also 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.

[Read: Alzheimer’s and Dementia Behavior Management]
Caregiving in the late stages of Alzheimer’s or dementia

As Alzheimer’s or another dementia reaches the late stages, your loved one will likely require 24-hour care. They may be unable to walk or handle any personal care, have difficulty eating, be vulnerable to infections, and no longer able to express their needs. Problems with incontinence, mood, hallucinations, and delirium are also very common.

In your role as caregiver, you’ll likely be combining these new challenges with managing painful feelings of grief and loss and making difficult end-of-life decisions. You may even be experiencing relief that your loved one’s long struggle is drawing to an end, or guilt that you’ve somehow failed as a caregiver. As at the other stages of your caregiving journey, it’s important to give yourself time to adjust, grieve your losses, and gain acceptance.

[Read: Late Stage and End-of-Life Care]

Since the caregiving demands are so extensive in the later stages, it may no longer be possible for you to provide the necessary care for your loved one alone. If the patient needs total support for routine activities such as bathing, dressing, or turning, you may not be strong enough to handle them on your own. Or you may feel that you’re unable to ease their pain or make them as comfortable you’d like. In such cases, you may want to consider moving them to a care facility such as a nursing home, where they can receive high levels of both custodial and medical care.

Another option is hospice and palliative care. While some facilities provide hospice care onsite, it’s more commonly provided in the patient’s own home. This allows your loved one to spend their final months in a familiar environment surrounded by family and friends, while you have the support of hospice staff to ensure your loved one enjoys the best quality of care until the end.

Connecting in the late stages of care

Regardless of the late-stage care options you choose, you can find a sense of reward in your caregiving role by making time each day to really connect with your loved one. Even though they can no longer verbally express love or appreciation, a late-stage Alzheimer’s or dementia patient can still connect through their senses.
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. As well as talking, you can also appeal to their senses by rubbing scented lotion into their skin, playing their favorite music, reading a meaningful book or poem to them, or viewing old photos together.

When you connect in this way, you’ll experience a process that boosts mood, reduces stress, and supports physical and emotional well-being—for both you and your loved one.

Don’t neglect your own needs

By always focusing so diligently on your loved one’s needs throughout the progression of their dementia, 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’re more likely to become overwhelmed and suffer burnout.

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.

[Read: Stress Management]

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.

Stay active. 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 you can’t get away for that long at once, break the time up into 10-minute sessions throughout the day.

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.
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Last updated: August 2021

References


Caregiver support

In the U.S.: Call the Alzheimer’s Association helpline at 1 800 272 3900 or the Alzheimer’s Foundation of America at 1-866-232-8484.

UK: Call the Alzheimer’s Society helpline at 0300 222 1122 or find support near you.

Australia: Call the Dementia Australia helpline at 1800 100 500 or find support in your region.

Canada: Find an Alzheimer Society in your area.
India: Call the Alzheimer’s and Related Disorders Society of India 24-hour helpline in your area.

In other countries: Browse a worldwide directory of Alzheimer associations for information, advice, and support near you. (Alzheimer’s Disease International)

Family Care Navigator – For caregivers in the U.S., a state-by-state resource to help you locate services and other resources. (Family Caregiver Alliance)

Caregiver Action Plan – Create a personalized action plan and find information, support, and local resources. (Alzheimer’s Association)