

Alzheimer's Awareness



Caring for Caregivers

It's important for caregivers to also care for themselves, and that's especially true for the difficult circumstances in which Alzheimer's caregivers find themselves.

Remember that each family is unique, just like each Alzheimer's treatment plan is unique. Then, try some of these things to take care of yourself so that you can better care for others.

BE A HEALTHY CAREGIVER

Staying physically and mentally strong is important, even as you take on more care of your family member with Alzheimer's. Make sure you see the doctor regularly, the Alzheimer's Association says. Get regular exercise, eat well and try to get plenty of rest.

The association says to pay attention to physical signs of too much stress such as stomach irritation and high blood pressure as well as changes in your behavior. Work with your medical providers on techniques to relax.

Know that you're doing your best and look for support groups to help you on your journey as a caregiver. The Alzheimer's Association has a directory of support groups on their website.



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RESPITE CARE

Respite care can provide Alzheimer's caregivers with a break from caring for their loved ones while still ensuring their loved ones are in a safe environment. Respite care can come at home from a friend or family member, or it can come

in the form of paid, in-home care services.

Adult day centers are also an option. Staff at day centers lead planned activities and often provide transportation and meals. These day centers can allow caregivers to go to work, run errands or just take time

for themselves. Some long-term care centers may also offer caregivers the chance to take a break, the association says, but insurance or Medicare may not cover their stay.

DEALING WITH GUILT

The Alzheimer's Association

warns that you may feel guilty about not being able to care for your loved one. Looking for help does not make you a failure, it says, and it's important to remember that these breaks may benefit the person with Alzheimer's as well as the caregiver.

Stages of Alzheimer's Disease

Alzheimer's can affect different people in different ways, but, generally speaking, the disease progresses in three stages, the Alzheimer's Association says.

Those are early, middle and late, or, in medical context, mild, moderate and severe.

EARLY/MILD ALZHEIMER'S

During the early stages of Alzheimer's, a person may still function independently, driving, working and taking part in social activities. However, they may forget things, such as familiar words or where they left their keys. Some signs may include difficulty in coming up with the correct word or name; difficulty remembering the names of new people; difficulty performing tasks; forgetting material they just read; losing a valuable object; trouble with planning or organizing.

MIDDLE/MODERATE ALZHEIMER'S

This is typically the longest stage of Alzheimer's disease, the Alzheimer's Association says. As this disease progresses, the patient will need increasing levels of care. Your loved one may get frustrated or angry, or act in unexpected ways. Some characteristics of this stage include:

- Being forgetful about personal history.



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- Feeling moody or withdrawn, especially during challenging situations.
- Being unable to recall basic information such as their address or phone number.
- Experiencing confusion about where they are or what day it is.
- Requiring help dressing for the season or occasion.
- Having trouble with bladder or bowel control.

- Changing sleep patterns.
- Showing a tendency to become lost.
- Demonstrating suspicious, delusional or compulsive repetitive behavior.

LATE/SEVERE ALZHEIMER'S

This is the final stage of Alzheimer's. Symptoms can be severe, with patients unable to respond to their environment,

have a conversation or control movement. Expect them to have difficulty communicating pain, the Alzheimer's Association says, along with significant personality changes.

During this stage, patients may need around-the-clock care and lose awareness of recent experiences and their present surroundings. Patients may also experience physical changes, such as difficulty

walking, sitting and swallowing. They may have difficulty communicating and become vulnerable to infections, particularly pneumonia.

Caregivers may consider using hospice care, which the Alzheimer's Association says can help provide comfort and dignity at the end of the patient's life and help families deal with the extensive changes in their loved one.

Disease Biomarkers

At present, diagnosing Alzheimer's disease relies on documenting the mental decline of patients.

By the time people are diagnosed, severe brain damage has already taken place. One promising path for an earlier diagnosis is using biomarkers to indicate the presence of disease.

WHAT ARE BIOMARKERS?

Biomarkers, or biological markers, can accurately measure and reliably indicate the presence of disease. An example is fasting blood sugar for diabetes.

There are several potential biomarkers for the early stages of Alzheimer's disease. These include beta-amyloid and tau levels in cerebrospinal fluid as well as brain changes detected in imaging.

USING IMAGING

One early sign of Alzheimer's might be a shrinkage in the hippocampus. Scientists agree on standardized values for brain volume loss, the Alzheimer's Association says. A standard workup for the disease should now include structural imaging such as an MRI or CT scan to show not only shrinkage of certain areas of the brain, but also damage from head trauma, a buildup of fluid in the brain, tumors, evidence of strokes or other underlying conditions.



Other imaging, such as a PET scan, can find reduced brain cell activity in certain regions of the brain. Alzheimer's is often associated with the reduced use of sugar in brain areas important to memory, learning and problem-solving. One of these scans is now a reasonable diagnostic test for people with a recent diagnosis of dementia and a documented cognitive decline

of at least six months who meet the criteria for both Alzheimer's and frontotemporal dementia.

TESTING CEREBROSPINAL FLUID

Cerebrospinal fluid is a clear fluid that bathes and cushions the brain and spinal cord. Most adults have about a pint of cerebrospinal fluid and physicians can sample that fluid

through a lumbar puncture, or spinal tap. Early Alzheimer's disease may cause changes in tau and beta-amyloid in cerebrospinal fluid. It may also cause an increased level of neurofilament light.

While there have been strides in standardizing the measurement of cerebrospinal biomarkers in the diagnosis of Alzheimer's, tests can still vary from institution to institution

and across testing platforms.

BLOOD TESTS

There may be consistent and measurable changes in blood levels of tau, beta-amyloid or other biomarkers. However, research is still taking place on this front. Today, blood tests are shaping clinical trials, the Alzheimer's Association says, and may soon be used in diagnosis in the doctor's office.

What Is Dementia?

Dementia is a term that encompasses any loss of memory, language, problem-solving or other mental ability severe enough to interfere with daily life.

It's an umbrella term, similar to heart disease, that covers a range of medical conditions.

Alzheimer's is the most common cause of dementia, accounting for 60-80% of dementia cases, the Alzheimer's Association says.

OTHER FORMS OF DEMENTIA

Vascular dementia occurs when there is microscopic bleeding and blood vessel blockages in the brain. It's the second-most common cause of dementia. Lewy body dementia is associated with abnormal deposits of a protein, alpha-synuclein, in the brain. The deposits, which are called Lewy bodies, affect chemicals in the brain and those changes, in turn, can lead to problems with thinking, movement, mood and behavior.

SIGNS OF DEMENTIA

Dementia causes and signs can vary greatly. Some symptoms are:

- Memory loss that disrupts daily life, such as forgetting important dates or events, asking the same questions, forgetting names or appointments.



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- Challenges in planning or solving problems, such as difficulty preparing meals or keeping track of monthly bills.

- Trouble completing familiar tasks, such as driving to a familiar location or remembering the rules of a game.

- Confusing time or place, such as where they are and how they got there.

- Difficulty understanding visual images and spatial relationships, such as determining color or contrast.

- Problems with words in speaking and writing, such as having trouble naming a familiar object or using the wrong name for something.

- Misplacing things and losing the ability to retrace steps.

- Exhibiting decreased or poor judgment, such as dealing with money or paying less attention to keeping themselves clean.

- Withdrawal from work or social activities, such as keeping up with a favorite team or activity.

- Changes in mood or personality, such as becoming more

suspicious or anxious.

Sometimes these symptoms are typical age-related changes. If you notice one or more of these symptoms, it can be a serious health concern that you should raise with a health care professional. Early detection of Alzheimer's brings more treatment options, such as clinical trials, and more time to plan.

Discussing Memory Concerns

Alzheimer's disease and memory challenges can be difficult subjects to broach, even among close friends and family.

The Alzheimer's Association says that it's best to speak to the person one-on-one, not in a group, so that they don't feel threatened. You should have the conversation as soon as possible; early detection and treatment is critical in Alzheimer's disease.

STARTING THE CONVERSATION

The Alzheimer's Association suggests conversation starters such as:

"I've noticed (these changes) in you, and I'm concerned. Have you noticed it? Are you worried?"

"How have you been feeling lately? You haven't seemed like yourself."

"I noticed you (specific example) and it worried me. Has anything else like that happened?"

You can also offer to go with them to the doctor, encouraging them along the way. You may have to have multiple conversations. Try making notes about each one so that you can plan for the next time you talk about it.

GOING TO THE DOCTOR

The Alzheimer's Association



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says that a skilled physician can diagnose Alzheimer's disease with more than 90% accuracy. You can contact your primary care physician, but you may also see a neurologist, a psychiatrist, a psychologist or a geriatrician.

Bring a list of any changes in your health, including specific examples of any memory changes you've had. You should

also list any of your past and current medical problems and whether any of your close family members have had memory problems. Bring your current prescriptions and any over-the-counter medications.

It's normal to feel anxious at these appointments, and that anxiety can cause you to forget questions you meant to ask. Before your appointment, write

down any questions you may have. They can include:

- What tests will be performed?
- What does each test involve?
- How long will the tests take?
- How long will it take to learn results?

LOOK FOR SUPPORT

The Alzheimer's Association has information and support

available. Visit its website at alz.org, or call a 24/7 helpline at (800) 272-3900. The association has master's level clinicians available to discuss your concerns. You can also find local support groups and a Training and Education Center to take online courses and learn more about Alzheimer's disease and dementia.

Memory Care Facilities

As Alzheimer's disease progresses, there may come a time where caregivers are unable to care for their affected loved ones at home.

Memory care units are often separate parts of long-term care facilities that have trained caregivers for people with dementia, including Alzheimer's disease.

STARTING YOUR SEARCH

You can start your search with your state department of social services or your local Council on Aging. Your loved one's doctor or health care team may also have recommendations, just make sure they are licensed by your state regulating agency. Make sure the memory care units you're considering are easy for you to get to so that you can visit regularly.

MAKING A VISIT

Contact each facility to schedule tours. Walk the halls, stay for lunch and watch activities. Meet the memory care unit's caregivers and ask questions, including whether you can speak to the family of another resident. Some questions to consider from the BrightFocus Foundation are:

- What kind of training do the caregivers have?
- How many caregivers work during each shift?



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- What is the ratio of residents to staff?
- How do the staff handle difficult behaviors?
- What is the plan if your loved one does not adapt to their new environment?
- Is the facility able to care for residents for the rest of their life?
- Can hospice come into the facility?
- What is the facility's plan

for emergencies?

DISCUSSING COSTS

Quality of care is, of course, your chief concern, but cost should be up there, too. Bright Focus suggests starting with the monthly fee, then talking about entry fees, rates for different levels of care and so on. Ask whether the facility works with long-term care insurance policies and wheth-

er there are any other expenses to discuss.

MEMORY CARE CERTIFICATION

The Joint Commission and the Alzheimer's Association came up with an enhanced certification for memory care facilities. This certification aligns with the Alzheimer's Association Dementia Care Practice Recommendations

and reflects the latest scientific research and best practices in memory care. These guidelines ensure person-centered memory care in a supportive and therapeutic environment with medical management, assessment and planning.

There are 56 total recommendations for dementia care. Certification in memory care costs about \$600 per year for a three-year certification.

Supporting Families

The Alzheimer's Association estimates that more than 11 million Americans are providing more than 18 billion hours of unpaid care to people living with dementia.

The association and the Alzheimer's Impact Movement are both working to implement public policies to support family caregivers.

VOLUNTEERING

The Alzheimer's Association offers a multitude of volunteer opportunities for anyone to get involved in the fight to end dementia. Volunteers can lend a hand to the Walk to End Alzheimer's, the world's largest fundraiser to fight Alzheimer's, or with other fundraising events in your community. The Longest Day, held annually on the summer solstice, is an event where participants around the world come together to fight the darkness of dementia. Fundraisers collect pledges and hold activities such as sports, exercises, games, arts, parties and more.

ALZHEIMER'S IMPACT MOVEMENT

The Alzheimer's Impact Movement is the advocacy affiliate of the Alzheimer's Association. It advocates for



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policies that help overcome dementia, including increased investment in research, improved care and support, and the development of approaches to reduce the risk of developing dementia. It works at both the state and federal level to advance these public priorities.

RIVALZ TO END ALZ

This is a series of flag football games to engage young

professional women across the country. Teams are organized around rivalries to inspire fundraising, awareness and action in the fight to end dementia. This year, the top RivALZ event in Houston raised more than \$170,000.

DO GOOD TO END ALZ

Do Good to End ALZ connects independent fundraising events to the Alzheimer's Association. There is no mini-

mum amount required for donation. Online giving is supported through the platform JustGiving, or you can donate by mail or even to your local chapter. While the Alzheimer's Association doesn't lend organizational or financial support to your fundraising event, it does provide an easy conduit for giving and provides some collateral support, such as printable fliers. Best of all, it's free.

PLANNED GIVING

Planned giving allows you to donate to the Alzheimer's Association and other charities through your final wishes. The organization offers sample language for your will or trust, charitable gift annuities, gifts from your retirement account, charitable remainder trusts, or a charitable lead trusts. Talk to your financial planner about the benefits of these types of gifts for your family.