

Caregiver Guide

It is our hope that the information contained in this guide will be of help to you on your journey with your loved one.



“Your Key to Support, Information, Education & Resources”

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The Diagnosis

Alzheimer's disease is a brain disorder named for German physician Alois Alzheimer, who first described it in 1906. Today we know that Alzheimer's:

- **Is a progressive and fatal brain disease.** As many as 5 million Americans are living with Alzheimer's disease. Alzheimer's destroys brain cells, causing problems with memory, thinking and behavior severe enough to affect work, lifelong hobbies or social life. Alzheimer's gets worse over time and it is fatal.
- **Is the most common form of dementia**, which is a general term for the loss of memory and other intellectual abilities serious enough to interfere with daily life. It is caused by physical changes in the brain.
- **Has no current cure.** But treatments for symptoms combined with the right services and support, can make life better for the millions of Americans living with Alzheimer's.

1. ***Let reality sink in.***

Whether you've suspected the diagnosis for a while or it comes as a shock, absorbing the reality is a critical process. Uncertainty about the disease's pace makes planning for the future difficult. Alzheimer's is a chronic disease that can possibly continue for many years with progressively more challenging stages that vary widely from person to person.

As you focus on your loved one's health, it is critical to stay aware of what you are experiencing and how it affects your life. Denial, grief, fear and financial worry are just some of the very common feelings the caregiver is expected to have. Talk to family members to get a reality check on how you're handling it.

2. ***Encourage your loved one to share the diagnosis.***

In the early stages, it's best to encourage your loved one to share the news with at least some close friends and family so that they can be a source of support. If your loved one refuses because they feel ashamed, tell them Alzheimer's is a physical disease like cancer and heart disease. There is no shame in being sick. If this becomes an issue, think about asking a nurse to talk to the patient about the benefits of talking about their diagnosis. Eventually, it may become necessary to discreetly tell close friends and family yourself.

3. ***Find support for you and your loved one.***

Trying to do everything yourself will leave you exhausted. Seek the support of family, friends and community resources. Joining a support group, whether local or online, may be a good source of comfort and reassurance. Confide in an inner circle of friends and family. Identify who can help you with day-to-day caregiver responsibilities.

4. *Get to know the turf.*

Take some time to learn a bit about what you're dealing with such as Alzheimer's stages, care-giving issues, medications and lifestyle practices that may stall the disease's progress.

5. *Have "the talk" about financial and legal inquiries.*

Have a frank talk with your loved one about their financial situation. You will need to know what resources are available as you plan ahead for the future care that will be needed. This is the ideal time to take the steps necessary to protect assets.

Reassure the patient that your goal is to help them maintain control, with some support from you (or someone else) when needed, rather than to take over control of their life. Plans may involve assets, wills and powers of attorney. You may explain that if your loved one doesn't handle these issues while they are able, you may have to go through expensive court proceedings to take care of these matters. If they refuse to make these decisions, coordinate a meeting with a professional to serve as a neutral third party.

6. *Plan ahead for care.*

It's possible that nothing in your loved one's life needs to change immediately following the diagnosis. One exception is driving. Now is the time for your loved one to give up the keys if they haven't done so already, since getting lost and poor judgment are hallmarks of the disease. Living independently in their home for as long as is practical can empower your loved one and perhaps slow the pace of decline. As judgment and skills become increasingly impaired, the patient will need more help. In the meantime, a basic outline of needs that will likely occur and possible ways to deal with them will help everyone feel prepared. Consider any care plan to be a work in progress that you will need to update and revise periodically.

7. *Get organized.*

Caregiving, finding resources and making decisions is not an easy task. The entire family should address caregiving issues. If the patient is capable, involve them in an open discussion of issues directly related to their future. If they are reluctant at first, persist. It is best to discuss their concerns now, while they are still capable. It is good to keep siblings well informed, preferably in writing.

Set up a file or binder to store their medical records, financial records, and personal information. It's best to do this now, while your loved one can help you gather information and give medical professionals permission to share information with you.

8. Get help

Now that you have an idea of the tasks and issues involved, take a deep breath and remember that you should ask for help. Caring for an Alzheimer's patient is not easy, and you deserve all of the support you can get. Avoid taking control of tasks that they can still perform. The more the patient is allowed to do on their own, the longer they will be able to maintain a sense of ownership over the course of their own life.

Start a list of the names and contact information of people who can help provide assistance: friends and family who can help. Keep a list of things to be done so that you will have an answer for those who ask what they can do to help. To help you get started, lists are provided in this booklet. Accept help on a regular basis. Discuss these things with family to keep everyone in the loop.

Remember that what you are doing is noble and generous. Whether or not your loved one is able to express it, they are fortunate to have someone who is willing and able to do the job you've taken on.

Stages of Alzheimer's

Each person with this disease is as unique as they were before disease. Many of us seek to explain the disease in stages, because knowing what might come in the future helps us prepare for it. The following stages of the disease were compiled by Ronald Peterson, MD, PhD, Director of Mayo Alzheimer's Disease Research Center.

Mild Alzheimer's

- Asking the same questions repeatedly
- Getting lost in conversations and having problems finding the right word
- Not being able to complete familiar tasks
- Not remembering recent events
- Misplacing items in inappropriate places
- Undergoing sudden changes in mood or behavior for no apparent reason
- Inability to concentrate or showing initiative
- Having less interest in their surroundings
- Showing indifference to their personal appearance
- Failure to show normal courtesies to others
- Disorientation to time and place
- Becoming lost while in familiar surroundings

Moderate Alzheimer's

- Forgetting to turn off appliances, like the iron or stove
- Consistently forgetting to take medications
- Having difficulty with tasks like paying bills or preparing a meal
- Having difficulty with tasks that require skilled movements
- Problems with communication, including reading and writing
- Exhibiting behaviors such as aggressiveness, outburst of anger, or withdrawal
- Behaving inappropriately in public
- Feeling increasingly agitated and restless, particularly at night
- Sleeping for long periods of time or hardly sleeping at all
- Having hallucinations or delusions

Severe Alzheimer's

- Having little or no memory
- Having difficulty speaking and understanding words
- Expressing little or no emotion
- Grasping objects or people and not letting go
- Having difficulty recognizing others, or even themselves in the mirror
- Needing assistance for all personal care
- Experiencing frequent incontinence
- Increasing weakness and being susceptible to infections
- Having difficulty chewing and swallowing, losing interest in food, losing weight
- Increasingly spending time in the bed or chair

Many caregivers find that their patient doesn't fit neatly into any one of these stages. It is critical to remember that each stage brings unique challenges for the caregiver. It is essential to take one day at a time, to take time for yourself and to do what is good for your patient and best for you. Give yourself permission to use all the help you can get.

Improving Daily Activities

- Adults with Alzheimer's are still adults. Treat your patient with dignity and respect.
- Adapt because your patient cannot change.
- Allow your loved one to participate at their highest level possible – while you still accept that they can no longer function independently.
- Post pictures or signs as cues to help your loved one find their way and use objects appropriately. Written reminders of often forgotten tasks and large labels on frequently used items, cabinet doors and drawers will make life easier for both of you.
- Appreciate good moments and good days. Learn to cherish the little things.
- Arguments will cause your patient to become even more confused and frustrated.
- Your actions, facial expressions and your tone of voice speak louder than words.

Be aware of what your presence communicates.

- It is important to encourage friends and family to visit often, but limit the number of guests at one time. Crowds, change in routine or surroundings may cause confusion.
- To help the patient with their sense of time, place a digital clock with large numbers where they will see it often. Set up a calendar with space for you to mark each day.
- If more than one person is a caregiver, post a list of specific responsibilities that each one should perform to prevent misunderstandings.
- You may provide your loved one with a notebook where they can, with your help, write down notes, details of conversations, and other day-to-day things they want to recall.

- Keep furniture and personal belongings consistent in all rooms. Rearranging furniture and personal belongings may cause confusion and anxiety.
- Use sturdy plastic plates to prevent breakage and injury.
- Prepare food that is easily eaten with fingers and provide bendable straws for drinks.
- Serve decaffeinated tea, coffee and soft drinks. Limit sugary foods and drinks.
- For bathing, use a shower chair or tub seat and a handheld shower wand.
- Lower the hot water heater temperature to 120 degrees to prevent scalding.
- Use non-skid mats in bathrooms, bathtubs and showers. Install grab bars in the bath.
- Choose loose fitting clothing with elastic waistbands and Velcro closures.
- Assess and reassess often. What is safe and effective for now, may not be so later.

Fire Safety

- Install smoke detectors and check and replace batteries regularly.
- Keep fire extinguishers accessible.
- Eliminate poor wiring and overloaded sockets.
- Do not use candles.
- If your loved one smokes, they may soon forget about smoking if you keep cigarettes and ash trays out of sight.

General Safety

- Post emergency numbers for doctor, police, fire, ambulance and readily available family members near a centrally located telephone.
- Disable automatic locks on storm and screen doors as to not get locked out, and hide an extra key in case it happens.
- Put decals on glass doors to prevent your loved one from walking into them.
- Lock up objects that might present a danger, such as matches, knives and firearms.
- Store medications, household cleansers and insecticides in a locked cabinet.
- Install outlet covers.
- Use sturdy chairs that do not tip.
- Either remove furniture with sharp corners or pad the corners.

- Remove fake fruit to prevent choking.
- Hide car keys if necessary or disable the car.

Wandering

Many people with brain impairment wander or pace. This is fine as long as the person is in a safe environment. Wandering can help relieve restlessness.

- Fence in your yard and swimming pool.
- Install additional locks, a motion detector or an alarm on exit doors to prevent your loved one from trying to leave without you knowing.
- Make sure your loved one wears a medical identification bracelet and have several recent photos of your loved one available in case they get lost.

Preventing Falls and Improving Mobility

- Make sure all lighting is maintained. Use nightlights in hallways and bathrooms.
- Install handrails in hallways and stairways and put a gate on the stairway.
- Install locks on the doors to the cellar/basement.
- Add non-skid strips and repair or remove carpeting on steps.
- Tape or paint stair edges to increase their visibility.
- Remove clutter that may cause falls, including rugs.
- Do not place electrical cords across walkways.
- Remove low furniture like coffee tables that might be a tripping hazard.

Sundowning

The term "sundowning" describes a symptom that often occurs in people with dementia such as Alzheimer's disease. The patient becomes increasingly confused and restless at the end of the day and can become progressively worse into the night. Sundowning is distressing for both the person with memory impairment and the caregiver. The cause isn't known, but factors that may aggravate late-day confusion include:

- Physical and mental fatigue sometimes caused by overstimulation
- Low lighting and increased shadows as the sun sets

Some tips for reducing this type of disorientation in your loved one:

- Limit busy activities, outside errands and visits from guests to morning or early afternoon. Encourage an afternoon nap or quiet time to reduce fatigue later.
- During the late afternoon and early evening, focus on maintaining a soothing environment. Eliminate background noise such as loud radios and televisions.
- Give the person a small, easy task such as folding small laundry items. Such a task will help keep the person occupied without overwhelming them.
- Make sure inside lighting is adequate at dusk. Turn on overhead lights to create well-lit areas and eliminate shadows.
- During the night, keep a night light on to reduce agitation that occurs when surroundings are dark or unfamiliar.
- In a strange setting such as a hospital, bring familiar items such as photographs or pillows.

A Word of Caution

Giving care to a disabled family member brings stress into the family. Caregiving often becomes the responsibility of one or two family members. This may cause resentment between the caregivers and family members who will not assume their share of duties. Unresolved conflicts or grudges among family members are likely to resurface. Clergy, social workers or counselors may be able to help resolve these issues.

Stay focused on what is best for you and your loved one. If your loved one is making unsafe choices or can no longer make decisions, look to their life long values and beliefs for guidance in making your decision about their care. It is important that you should one day be able to look back upon this period of time with no regrets.

You may have had a loved one say to you, “Promise you’ll never send me to a nursing home.” This request usually reflects what most of us want: to stay in our own homes and to maintain our independence. Think carefully before making such a promise. Agreeing that you will not “put someone” in a nursing home may close the door to the right care option for your family. Such a promise seriously hampers one’s ability to do what is necessary, either for their own health or for their loved one. Many people discover too late that the promises they once made can no longer be kept.

Base your promises and decisions on a realistic assessment of the current situation or diagnosis, and realize that you may need to revisit your agreement. It may be best to simply promise, “I will make sure you have the very best care we can arrange. I can’t think of a situation where I’d walk out on you.” You truly do not know what will happen in the future. Disease and illness can lead to enormous changes. It’s not only your loved one’s health that changes—your own health may alter over time as well. The fact is that for some illnesses, professional health care in a long-term care facility is the only reasonable choice.

If you have made such a promise to a loved one, and now wish you had not – consider what you would like done for yourself if the situation were reversed.

Selecting a Nursing Home

If you begin to feel that nursing home placement may be necessary for your loved one, start visiting the homes you think would best meet their needs. Many nursing homes have special care units for patients with dementia. You will want to make an unannounced visit to the facility to evaluate the surroundings and meet the staff. Prepare a list of questions beforehand so that you are sure to get all the information you need. Once you find a facility that is appropriate for your loved one, get their name on the waiting list even if you are not ready to move them at that time. You may want to call every few months to make sure their name is still on the list.

The Director of Nursing or the Administrator will address any problem or complaint about the care of a person living at a nursing home. If the problem is not resolved, caregivers may make a report to the Marshall County Ombudsman at 1-800-243-5463. An ombudsman is an advocate for residents of nursing homes and assisted living homes and will investigate complaints and help resolve problems.

Caring for the Caregiver

The most loving and responsible thing you can do for your loved one is to stay as physically and emotionally healthy as you can. Caring for a person with memory loss and confusion can be exhausting. You will be better able to care for someone else if you are feeling healthy. Your genes determine some aspects of how you grow old and your risk for developing dementia but life choices and healthy behaviors play the biggest role in determining how well you age and how many diseases occur that damage your brain. You can't change your genes, but you can control your lifestyle. Suggested tips:

Visit your doctor on a regular basis and follow their advice to:

- Control levels of cholesterol and triglycerides.
- Identify and treat depression. Untreated depression may produce memory problems that resemble dementia, and may improve with medications.
- Monitor blood pressure.

Control alcohol consumption. Alcohol-induced dementia is one of the five most common causes of intellectual loss in the older person. Anyone with memory difficulty over the age of 65 should stop drinking alcohol as it worsens confusion in the older person, even those who do not suffer from dementia.

Do not smoke. Exercise at least three times a week and get adequate rest.

Limit caffeine, sugar and salt. Eat nutritious meals and maintain a healthy weight.

To promote your physical and mental well being, maintain spiritual and religious practices that are important to you.

Be aware of your stress level. Arrange to have free time often to go to church, see a movie, go for a walk, shopping or to meet friends for lunch. It is important to have a life outside your caregiving duties.

Use your head: continue to learn new things, read and engage in mental activities such as crossword puzzles.

Find a support group where you can share your feelings and concerns.

Caregiving involves a range of emotions. When you find that your emotions are intense, consider the following causes:

- That you are grieving a loss.
- That you are experiencing increased stress.
- That you need to make a change in your caregiving situation.

Many caregivers find it difficult to ask for help, particularly those who are spousal caregivers. They feel that nobody else could possibly care for their loved one as well as they can. You have to be able to tell yourself that it's okay to ask for what you need. Allow those who also love your spouse the opportunity to show their love by helping. Others may want to help you but don't want to intrude. They need for you to ask.

Figuring Out What Needs to Be Done

This is a checklist to help you determine what your loved one may need. Don't let it overwhelm you. Simply use it to make your own list of things to do or to learn about.

Full Name _____

Social Security Number _____

Location of:

Safety Deposit Box, Keys & Number _____

Birth Certificate _____

Marriage Certificate/Divorce Records _____

Military Records _____

Auto Title/Registration _____

Bonds, CDs, Stocks _____

401(k)/IRAs _____

Trusts _____

Deed to Property _____

Insurance Policies:

Auto _____

Homeowners _____

Health _____

Life _____

Long-Term Care _____

Mortgage Information _____

Advance Directive/Living Will _____

Durable Power of Attorney _____

Name and Number: _____

Organ Donor Card _____

Prepaid Funeral/Cemetery _____

Will _____

Doctors: Name & Number _____

Pharmacy _____

Clergy Name & Number _____

Figuring Out What Needs to Be Done, Page 2

Bank Name & Number _____
Checking Account Number _____
Savings Account Number _____
Credit Cards _____
Bank Statements _____
Income Tax Records _____

Monthly Income: _____

Monthly Expenses: _____

Outstanding Loans: _____

<u>My family and friends:</u>	<u>Things they can do to help me:</u>
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Information To Share When Leaving My Loved One In Another's Care:

My Loved One's Name: _____

My Loved One's Favorites:

Foods: _____

Beverages: _____

Family & Relation: _____

Friends: _____

Pets: _____

Places: _____

Past Experiences: _____

Songs or Music: _____

TV Show: _____

(List Channel & Time) _____

Radio Station: _____

Movie: _____

Suggestions To Soothe My Loved One:

Daily Routine:

Rising Time _____

Snack Times _____

Bath Time _____

Nap Times _____

Meal Times _____

Bed Time _____

Needs Assistance with: _____

Avoid These Things That Upset My Loved One:

Primary Caregiver's Name & Phone: _____

Relationship to Loved One: _____

Contact # 1 Name, Relation & Number: _____

Contact # 2 Name, Relation & Number: _____

Medications to Administer and Times: _____

Avoid These Foods: _____

Special Instructions While I'm Away: _____

Resources

ALABAMA MEDICAID AGENCY

District Office: Toll Free 1-866-371-4077

www.medicaid.state.al.us

DEPARTMENT OF PUBLIC HEALTH, ALABAMA

Links to order birth & marriage certificates, Lists nursing homes & assisted living centers

www.adph.org

MARSHALL COUNTY 582-3174

INCONTINENCE SCHOLARSHIP PROGRAM

279-0922 Alzheimer's Services of Marshall County provides incontinence products free of charge delivered monthly to the homes of qualifying patients.

NURSING HOMES WITH ALZHEIMER'S UNITS

- Attalla Health Care 915 Stewart Avenue Attalla, AL 35954
256-538-7852
- Barfield Health Care 2244 U. S. Hwy. 431 Guntersville, AL 35976
256-582-3112 www.barfieldhealthcare.com
- Collinsville Health Care P. O. Box 310 Collinsville, AL 35961
256-524-2119
- Golden Living Center, Arab 235 3rd Street S.E. Arab, AL 35016
256-586-3111 www.goldenlivingcenters.com
- Golden Living Center, Boaz 600 Corley Avenue Boaz, AL 35957
256-593-8380 www.goldenlivingcenters.com
- Merrill Gardens 151 Woodham Drive Albertville, AL 35951
256-878-3132 www.merrillgardens.com

RESPIRE CARE AND SERVICES

These in home care agencies are not ASMC home care agencies and we are not responsible for services rendered by these agencies:

- Alabama Cares **Available to seniors 60+**
800-243-5463 Supports caregivers by providing training and assistance.
- Caring Companions Hospice of Marshall County, Shepherd's Cove
256-891-7724 408 Martling Road Albertville, AL 35951
888-334-9336 www.hospicemc.org
- Comfort Keepers 218 Rhett Ave., Suite 128 Huntsville, AL 35801
256-382-0426 www.comfortkeepers.com
- Home Instead Senior Care 2715 Spring Gate Road Huntsville, AL 35802
256-505-3100 Guntersville www.homeinstead.com
256-883-3080 Huntsville

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SOCIAL SECURITY ADMINISTRATION

891-0672

SUPPORT GROUPS

These support groups are not ASMC support groups and we are not responsible for services rendered by these groups:

- Gilliam Springs Baptist Church 1351 N Brindlee Mountain Pkwy. Arab, AL 35016
256-586-3147 mbishop@gilliamsprings.org
- Golden Living Center, Arab 235 3rd Street S.E. Arab, AL 35016
256-586-3111
- Golden Living Center, Boaz 600 Corley Avenue Boaz, AL 35957
256-593-8380, Karen Hill 3rd Thursday at 6:00 p.m.
- Grant Church of Christ 4197 Cathedral Caverns Hwy. Grant, AL 35747
256-728-2030, Bill Vinson 2nd & 4th Wednesdays, 1:00 p.m. wilshire@neph.net
- Merrill Gardens 151 Woodham Drive Albertville, AL 35951
256-878-3132, Kim Benson marketing.albertville@merrillgardens.com

UNITED WAY'S FIRST CALL FOR HELP Resource of community services

582-0506

VETERANS AFFAIRS

571-7761

RECOMMENDED READING: THE 36-HOUR DAY

A Family Guide to Caring for Persons With Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life by Nancy L. Mace, MA and Peter V. Rabins, MD