

# The Dementia Companion

A Guide for Family and Care Partners



# Contents

Welcome .....pages 3

Wondering and Worried .....page 5

Mild Cognitive Impairment .....page 7

Eary Stage Dementia.....page 9

Mid Stage Dementia .....page 12

Late Stage Dementia.....page 14

Dementia Quick Reference .....page 17

Communication Tips.....page 19

Resources .....page 21

Action Steps Summary .....page 25

# Dementia Road Map Overview

## Wondering and worried

- ✓ Is everything ok?
- ✓ Should my loved one be checked by a health care professional?
- ✓ What if my loved one won't go to a health care professional?

## Mild Cognitive Impairment (MCI)

- ✓ Where do we go to get memory loss checked out?
- ✓ How can I help my loved one with their memory and thinking?
- ✓ What can we do to promote our loved one's well being?

## Early Stage Dementia

- ✓ Are there any medication, treatments or lifestyle changes that could help my loved one's memory and thinking?
- ✓ How can we help our loved one stay active and connected?
- ✓ Should my loved one still be driving?
- ✓ Is our legal paperwork in order?

## Mid Stage Dementia

- ✓ What can I do to make the home safer?
- ✓ What do we do if our loved one won't stop driving?
- ✓ Where do we get help in coping with behaviors?
- ✓ What services might help and where do I find them?

## Late Stage Dementia

- ✓ What can we do to promote quality of life?
- ✓ What kind of care is best for my loved one?
- ✓ What do we want in terms of medical care at the end of our loved one's life?

# A Guide for Family and Care Partners

Caring for a person living with memory loss or dementia is a journey, one that can last for many years, and if filled with twists and turns. The journey is not a straight path through stages each person with Alzheimer's or other type of dementia may progress differently and in their own time. Family members who are companions on this journey will need information, support and guidance along the way.

Most families report they are not prepared for life with dementia and that they would welcome some type of "Companion." This document is designed to be just that. It provides a look at the big picture and walks along side the family or care partner and offers tips about what to expect, what decisions lie ahead, and what steps to take.

## Worried about memory loss in a loved one?

If you're worried about your loved one's forgetfulness, feel it's getting worse or that the memory problems are starting to interfere with everyday life, it's time to talk to a health care professional.

Why is "getting checked" important? Because there are benefits to identifying and addressing memory loss, including:

- ✓ To find out what may be causing the problems there are reasons for memory loss and confusion that are treatable. Some conditions that cause dementia, such as normal pressure hydrocephalus, thyroid problems or a vitamin deficiency, are treatable or reversible. Even if it turns out to be a type of dementia, it's best to get a diagnosis and help early in the disease process.
- ✓ A health care professional can provide better clinical care for all your medical conditions with a diagnosis, when they understand what is happening.
- ✓ You, your loved one and other family members can more easily plan for the future when you know what you are dealing with. A diagnosis makes taking the next steps a bit easier.

# Guides for the Journey

For every caregiver we whole heartedly recommend contacting at least two agencies in your community to guide and support you.

- Area Agencies on Aging (AAAs) are trusted sources of information and assistance, where older adults can turn to find specialized information, supports and service options in their area. They also offer Family Caregiver Support Programs that assist family members as they are helping a loved one with dementia or other conditions. AAAs are sometimes known as "The Department of Elder Affairs" or "Aging and Disability Resource Center". Visit <https://elderaffairs.org/resource-directory/aging-and-disability-resource-centers-adrcs/> or [https://www.careforflorida.org/list10\\_florida\\_Aging\\_Services\\_senior\\_centers.htm](https://www.careforflorida.org/list10_florida_Aging_Services_senior_centers.htm)
- The Alzheimer's Association has free literature on all things dementia available in English and Spanish, 24/7 phone support (in a caller's preferred language through a translation service), the latest information on brain health, available medications for people with dementia, support groups, trainings, and care consultation to help with decision making. The Alzheimer's Association serves people living with memory loss or any types of dementia as well as their families and caregivers. Visit <https://www.alz.org/seflorida> or call 800-272-3900.
- Another resource guide in Florida is available through the Alzheimer's Community Care Program. Visit <https://www.alzcare.org/> for more information.

## Alzheimer's and dementia - what's the difference?

- Dementia is a general term referring to a loss of cognitive function remembering, thinking, and reasoning severe enough to interfere with everyday life.
- Dementia is not a specific disease, but an overall term describing a wide range of symptoms. It is not normal aging. Dementia is caused by damage to the brain from disease or trauma.
- Alzheimer's disease is the most common cause of dementia. Other causes include vascular dementia, Lewy body dementia, and frontotemporal dementia.

For more information: <https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia>

# Wondering and Worried

## You may be wondering

- Is everything OK?
- Should my loved one be checked by a health care professional?
- What if my loved one won't go to a health care professional?

## What should you expect in this stage?

You notice changes in your loved one's memory, and thinking, but they may or may not affect daily life activities.

For example, you may notice that they:

- Have difficulty performing more than one task at a time.
- Have difficulty solving complex problems or making decisions.
- Forget recent events or conversations.
- Take longer to perform more difficult mental activities such as using the computer.

Your loved one is likely concerned but may not discuss it. Other friends and family may or may not see or notice any changes.

## What you can do

- Keep track of changes you notice. If your loved one doesn't bring it up, find the right time and a sensitive way to discuss these changes with them - get it out in the open.
- Ask your loved one to have a complete medical check-up. It's important to know if memory and thinking changes may be caused by something that could be treated or reversed. Even if not, it's best to know what you're dealing with.
- If your loved one is resistant to a medical check-up, enlist the help of trusted family or friends who may be able to encourage this.
- Call and ask your loved one's health care professional for the Medicare Annual Wellness visit (if they are on Medicare) that should include a cognitive assessment along with other screenings. Feel free to share with the professional what you've noticed about changes in memory or thinking - either in person, via phone or in a letter.

- If you don't feel comfortable with your loved one's current health care professional, try to find a new one. Most primary care professionals can diagnose dementia. But if you're looking for a specialist, contact the Alzheimer's Association to help identify providers in your area.
- If you know or suspect your loved one has hearing loss, get it checked and addressed - hearing loss makes it harder for a person with memory loss or confusion to communicate. This can lead to misunderstandings and social isolation.
- Make sure both you and your loved one are making healthy lifestyle choices:
  - > Stay active and engaged in social groups, arts, and other activities of interest.
  - > Eat fresh fruits and vegetables.
  - > Be physically active.
- Make it a priority to begin and/or complete legal, financial and **advance care planning**, including essential planning documents. While all adults should have a plan in place in the event of one's disability or death, such planning is even more important for anyone beginning to experience changes in memory or thinking abilities. While such changes may or may not end up being dementia, it is critical to complete this planning while your loved one has the ability to do so.

## Action steps

The following steps are important at this point:

- ✓ Obtain a medical assessment to find out what may be causing the problems. Complete health care planning documents. Your loved one should have:
  - > A Health Care Directive (also called a "living will" or "advance directive" regarding treatment preferences); and
  - > A Durable Power of Attorney for Health Care, appointing a health care "agent."
- ✓ Complete a General Durable Power of Attorney document. In this document, your loved one appoints an "agent" to assist with financial and related matters.
- ✓ Complete an estate plan. Your loved one's estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- ✓ Have a family meeting to discuss what's happening, and necessary next steps.

# Mild Cognitive Impairment (MCI)

Mild Cognitive Impairment (MCI) is a slight but measurable decline in cognitive abilities that includes memory and thinking. MCI is not dementia. While a person with MCI is more likely to develop dementia, this may or may not occur.

## You may be wondering

- Where do we go to get memory loss checked out?
- How can I help my loved one with their memory and thinking?
- What can we do to promote our loved one's well being?

## What should you expect in this stage?

Your loved one is still independent but may have difficulty paying bills, preparing meals, shopping, driving.

## They may:

- Forget details
- Display less ambition
- Have emotions that go up and down
- Be more reliant on you

Your loved one may find particular success in completing familiar routines and habits.

## You may:

- Feel irritation with loved one's differing abilities.
- Also feel compassion for loved one's changes.
- Find that other friends and family don't notice changes in your loved one or understand your concerns.

## What you can do

- If not yet evaluated, ask your loved one's health care professional for the Medicare Annual Wellness visit it includes detection of cognitive impairment along with other screenings.
- Ask your loved one if you can attend and participate in their medical appointments.
- Inquire about lifestyle changes that may be helpful to overall wellness and functioning.
- Consider keeping a notebook about your loved one's changes and needs (such as new or different behaviors, medication changes or effects, abilities to take care of finances or appointments)
- Instead of thinking that your loved one should just "try harder" remind yourself that they are doing the best they can.

- Tell your own health care provider that you are caring for a loved one with cognitive impairment so they can be aware of potential health related risks (related to caregiver stress)
- Learn more about Mild Cognitive Impairment (MCI).
- Be generous with your patience.
- Consider paying bills and shopping together so your loved one can have successes.

## To help your loved one

- Support them in managing any heart conditions, high blood pressure or diabetes as needed. This may include helping them to manage medications. See tips online at <https://www.nia.nih.gov/health/managing-medicines-person-alzheimers>
- Encourage a healthy lifestyle including regular exercise, a healthy diet, and social activities.
- Encourage the use of long time skills, like playing the piano, singing, typing, crafts, or speaking a second language.
- Share (and read) the booklet - "Living Well with MCI or Early Dementia" from the Alzheimer's Association online at [www.alzheimersinfo.org/AlzheimerInfo/livingwellguide](http://www.alzheimersinfo.org/AlzheimerInfo/livingwellguide)

## Action steps

The following steps are important at this point. Remember! If your loved one has not yet had a medical assessment, contact their health care professional, a Geriatrician, a Neurologist, and/or a Neuropsychologist.

- ✓ Discuss with loved one the issue of when to discontinue driving. Review the Dementia Legal Planning Toolkit at [https://www.alz.org/help-support/i-have-alz/plan-for-your-future/legal\\_planning](https://www.alz.org/help-support/i-have-alz/plan-for-your-future/legal_planning)
- ✓ Complete health care planning documents. Your loved one should have:
  - > A Health Care Directive (also called a "living will" or "advance directive" regarding treatment preferences); and
  - > A Durable Power of Attorney for Health Care, appointing a health care "agent."
- ✓ Complete a General Durable Power of Attorney document. In this document, your loved one appoints an "agent" to assist with financial and related matters.
- ✓ Complete an estate plan. Your loved one's estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- ✓ Encourage other family and friends to visit regularly.
- ✓ Have a family meeting to discuss what's happening, and ways to support the person with memory loss, such as: encouraging a check up with a health care provider, managing safe medication use, and/or helping with finances or legal planning.



# Early Stage Dementia

## You may be wondering

- Are there any medications, treatments or lifestyle changes that could help my loved one's memory and thinking?
- How can we help our loved one stay active and connected?
- Should my loved one still be driving?
- Is our legal paperwork in order?

## What should you expect in this stage?

Your loved one has difficulty accomplishing some activities. Common difficulties include:

- Coming up with the right word or name.
- Forget names of familiar people and things.
- Have decreased performance in work or social situations.
- Have trouble multitasking.
- Take more time to process information.
- Write reminders and lose them.
- Have mild mood and/or personality changes.
- Feel sorrow, suspicion, anger, frustration.
- Have more trouble driving safely.

At the same time, you may find that your loved one has some kinds of memory that work quite well.

## They will likely

- Remember stories from long ago
- Remember how to do things that they are familiar with (like playing an instrument)
- Focus more on the present moment
- Enjoy a sense of humor

## What you can do

- Be an advocate for the right diagnosis and best health care. If you're not happy with current care, find a health care professional that will work with you and your loved one together.
- Learn all you can about the disease and tips for communicating supportively with your loved one.
- Make your life a no guilt zone.

- Put safety measures in place before they're needed related to falls, wandering, medication use, harmful cleaning products, guns, power tools, etc.
- Embrace the good days and prepare yourself for the stormy ones.
- Keep up health and wellness appointments for yourself.
- Make efforts to get a good night's sleep every night.
- Seek out support and reassurance: talk with others who have had a similar situation (e.g., early memory loss support group) or call the Alzheimer's Association Helpline.
- Explore how your loved one wants to live at the end of their lives. Learn about "having the conversation," through the "Conversation Starter Kit for Families of Loved Ones of People with Alzheimer's Disease or other Forms of Dementia."
- Encourage your loved one to use the in depth dementia advance planning legal document in Washington State, "Living with Dementia Mental Health Advance Directive" to document their wishes about anticipated challenges throughout the progression of the disease (such as when to stop driving, where they want to live, who provides their care).

## To help your loved one

- Provide "Living with Alzheimer's: Taking Action Workbook." (See Resources)
- Go along on medical appointments if your loved one agrees. If they do not want this, try calling the practitioner ahead of appointments to share concerns.
- Create and stick to simple routines.
- Monitor that any medications are taken properly.
- Assist them to continue activities of interest.
- Promote the best functioning possible. Get hearing loss and vision checked regularly. Make sure hearing aids and glasses are in good condition and used as needed.
- Resist the urge to step in and do things for them; allow more time, and occasional errors.
- Encourage them to attend an early stage support group and seek out dementia-friendly recreation activities.
- Consider enrolling in a clinical trial or research study on dementia at a university or memory clinic. Your loved one may advance our understanding of dementia and help in the effort to develop new treatments.
- When you see behaviors that are "out of character," do NOT take these personally - recognize it's the disease.
- Help family and friends understand how to communicate and interact - if needed you can share what they like to do, how to start a conversation, the need to avoid correcting and arguing.

- Look for ways to modify your loved one's favorite activities rather than give them up.
- Consider ways to protect yourself and your loved one from financial missteps and exploitation such as removing your loved one's credit cards (or lower credit limits) and other key wallet documents.

### Services to consider

- Educational workshops
- Powerful tools for caregivers classes
- Alzheimer's/dementia seminars
- E-Learning and online courses
- Get connected online - try the Alzheimer's Navigator, ALZConnected online community or e-learning modules offered through the Alzheimer's Association and/or the "Alzheimer's Reading Room."
- The Alzheimer's Association collaborates with the MedicAlert Foundation which uses a community support network, including the police, to locate your loved one in case they wander. Visit [www.alz.org/care/dementia-medic-alert-safe-return.asp](http://www.alz.org/care/dementia-medic-alert-safe-return.asp) to learn more. Or, look into locator aids that use active GPS capability (real time tracker).
- Consultants who specialize in caregiving and/or dementia may be available through your Community Living Connections or the Alzheimer's Association.

### Action steps

The following steps are important at this point. See **Action steps on pages 6 and 8**, and do the following:

- ✓ If your loved one is still driving, review together the booklet "At the Crossroads: Family Conversations about Alzheimer's, Dementia and Driving"
- ✓ Make sure your loved one either carries ID or wears MedicAlert jewelry.
- ✓ Discuss with your loved one their wishes for end-of-life care, and document these as decisions are made.
- ✓ Have a family meeting to discuss what's happening and next steps, such as ways the family can support the person with memory loss to stay active, healthy and socially engaged, or help you with decisions and planning around driving or other safety concerns.
- ✓ Make a back up plan to be used if something happens to you.
- ✓ Contact the **Alzheimer's Association and/or Dementia Support Northwest (NW Washington)** for dementia related information, education and support opportunities.
- ✓ Contact your local Community Living Connection and Family Caregiver Support Program to find out more about local support services.

## Mid Stage Dementia

### You may be wondering

- What can I do to make the home safer?
- What do we do if our loved one won't stop driving?
- Where do we get help in coping with behaviors?
- What services might help and where do I find them?
- How can I make my loved one's life more enjoyable?

### What should you expect in this stage?

In the middle stage, (often the longest) confusion becomes more obvious. Your loved one will have increasing needs for care and supervision.

### They may:

- Have more trouble with memory - such as recalling their own address or personal history.
- Have problems organizing, planning, following instructions and solving problems.
- Not recognize familiar people.
- Forget how to initiate routine tasks or how to complete them, including health and hygiene care.
- May resist bathing or other personal care.
- Have trouble controlling their bowel or bladder.
- Lack judgment and develop the following behaviors:
  - Trouble sleeping
  - Apathy, passivity
  - Irritability, aggressive talk and actions
  - Clinging (following you around)
  - Repetitive questions
  - Wandering
- Have delusions (false beliefs) or hallucinations (seeing/hearing things that aren't there).
- Have more problems with balance (increasing the risk for falls).
- Be increasingly sensitive to caregiver mood and behavior.

## You may:

- Feel tired, stressed, lonely, isolated, angry, or irritable.
- Be wondering if you need assistance, or how long you can do this.
- Notice that other friends and family are wondering how to help, sometimes wanting to take over the care.

## What you can do

At this stage, **you will need** the following kinds of support:

- Daily relief from care tasks (sometimes known as Respite Care)
- A network of caring friends and family
- Time to manage your own self care
- Establish or maintain routines for you and your loved one.
- Try not to mistake loved one's moodiness for rudeness.
- Practice not taking behaviors personally - it's the disease.
- Ask for help with taking care of the home or providing care - housekeeping, errands, yard care, handy person, or in home assistance for your loved one.
- If you get unwanted opinions or criticisms, take a step back and recognize that others may be trying to help - see if you can work out a plan for them to assist in some way. Recognize that you are doing the best you can.
- Attend a support group.
- Vent as needed with trusted friends or other caregivers.
- Take safety precautions related to falls, wandering, medication use, harmful cleaning products, guns, power tools, etc.
- If your loved one is still driving, enlist the help of their health care provider to get them to stop. Call the Alzheimer's Association for additional ideas.
- Look into support and service options to help maintain current living arrangement, such as in home care or adult day services.
- Investigate residential care options in your area in the event they are needed in the future. These might include adult family homes, assisted living, and/or nursing homes. Look into their costs and take tours so you'll be prepared if you need to make a decision quickly.

## To help your loved one

- Encourage family and close friends to learn communication tips and techniques - and to help provide activities your loved one still enjoys. Refer them to the Alzheimer's Association website or 24/7 toll-free Helpline: **800-272-3900**.

- Try to provide kindness, understanding, and acceptance.
- Channel their energy - go for regular walks together, encourage them to help with chores like vacuuming, sweeping, folding laundry, gardening.
- Simplify tasks and activities, break into smaller steps - allow more time for your loved one to accomplish them.
- Reminisce - look at old photo albums, a memory book or old videos.
- Make sure your loved one gets ongoing medical care.
- If you notice any SUDDEN changes in behavior, call your loved one's physician - this can be a sign of an infection or other medical issue.
- Talk to their doctor about completing a Portable Orders for Life-Sustaining Treatment (POLST) form, and ask for a referral to a Physical or Occupational Therapist for a home safety evaluation.
- Go to the Alzheimer's Association's online "Caregiver Center" to find helpful tips on daily care such as activities, providing personal care and managing incontinence. Visit <https://www.alz.org/help-support/caregiving> to learn more.

## Services to consider

- Education workshops or conferences for caregivers.
- Technology to assist with a variety of tasks - reminders, cameras, chimes to alert if an exterior door opens, etc.
- Adult day services offer your loved one activity, exercise and socialization and provides you with some time for yourself.

## Action steps

See **Action steps on pages 6, 8, and 11** and do the following:

- ✓ Request a home safety evaluation with a Physical or Occupational Therapist to make the home safer and home care tasks easier.
- ✓ Update your back up plan to be used if something happens to you.
- ✓ Have a family meeting to discuss what's happening now and ways to support your loved one and you, and any next steps as care needs increase.
- ✓ If help with financing care is needed, contact your local Community Living Connections or Home and Community Services office. Find these at [www.waclc.org/connect](http://www.waclc.org/connect)
- ✓ Complete end - life-planning. Discuss and document how your loved one wants to live at the end of their life, including medical care wanted or not wanted, comfort measures, and palliative and hospice care.



# Late Stage Dementia

## You may be wondering

- What can we do to promote quality of life?
- What kind of care is best for my loved one?
- What do we want in terms of medical care at the end of our loved one's life?

## What should you expect in this stage?

In the late stage, your loved one is completely dependent for personal care activities.

## They may:

- Not recognize you or others by name. This does not mean they don't know (or feel) who you are.
- Have increasing difficulty communicating may use "word salad" (mixed up words), or be speechless. Nonverbal communication may work best.
- Be frequently or totally incontinent.
- Experience changes in physical abilities including ability to walk, sit and eventually swallow.
- Have rigidity, immobility, jerks or seizures.
- Be feeling deep emotions and may scream, moan, or fail
- Be vulnerable to infections, especially pneumonia. At the same time, you may notice that they are still attuned to the emotions of others, enjoy companionship, respond to physical touch or music, and can encourage others to slow down and focus on the present.

## You may:

- Experience profound grief.
- Become aware that the end of life for your loved one is near.
- Find that friends and family are also experiencing grief.

## What you can do

- Be gentle with yourself and your loved one. Respect yourself for the love and support you have provided for your loved one and yourself.

- Allow plenty of time for tasks and activities - don't rush.
- Be together in ways that don't require words.
- Actively seek palliative care and/or hospice care.
- Review with your loved one's health care professional any health issues and their related medications that could be reduced or discontinued.
- Consider what kind of emotional support you may want or need during the period near and after death.
- Attend a support group.
- Consider including your closest friends and family in discussions about the end of life preferences and plans that have already been made.

## To help your loved one

- Maintain simple routines with a mix of rest and activity. Get outdoors for fresh air - go for walks, sit on porches.
- Recall important life events or achievements - use photos or videos.
- Music is a common denominator for many people - try playing music that your loved one enjoys. Sing!
- Appeal to the senses - squeeze fresh orange juice, smell the roses, use scented lotions.
- Encourage other family and friends to visit on a regular basis.
- They may not be verbal or ambulatory, but still appreciate kind words, loving hugs, and comfort.

## Services to consider

- In-home or residential care
- Palliative care and hospice care
- Support group
- Counseling or other emotional support for yourself

# Dementia Quick Reference

## Ten warning signs of Alzheimer's

1. Memory loss that disrupts daily life.
2. Challenges in planning or solving problems.
3. Difficulty completing tasks at home, at work or at leisure.
4. Confusion with time or place.
5. Trouble understanding visual images and spatial relationships.
6. New problems with words in speaking or in writing.
7. Misplacing things and losing the ability to retrace steps.
8. Decreased or poor judgment.
9. Withdrawal from work or social activities.
10. Changes in mood or personality.

For more information on "10 Early Signs and Symptoms of Alzheimer's and Dementia" go to: [https://www.alz.org/alzheimers-dementia/10\\_signs](https://www.alz.org/alzheimers-dementia/10_signs)

## Early Stage Alzheimer's Disease

- Trouble with time or sequence of events.
- Trouble multi-tasking.
- Having more trouble driving safely
- Increasing indifference to normal courtesies of life.
- Forgetting names of familiar people and things.
- Taking more time to process information.
- Mild mood and/or personality changes.
- Decreasing performance in work or social situations.
- Increased preferences for familiar things.
- Feeling sorrow, suspicion, anger, frustration.

## Mid Stage Alzheimer's Disease

- Increasing needs for care and supervision.
- Problems organizing, planning, following instructions and solving problems.
- Forgetting how to initiate or complete tasks, including health and hygiene care.
- Abilities that vary from one day to the next.
- More problems with balance (increasing the risk for falls).
- Not being able to contribute to family life in traditional ways.
- Lacking judgment and developing the following behaviors: trouble sleeping, apathy, passivity, irritability, aggressive talk and actions, clinging (following you around), repetitive questions, wandering.
- More trouble with memory such as own address or personal history.
- May complain of neglect or blame others when things go wrong.
- Not recognizing familiar people.
- May resist bathing or other personal
- Delusions (false beliefs) or hallucinations

## Late Stage Alzheimer's Disease

- Dependent for personal care activities.
- Changes in physical abilities: ability to walk, sit and eventually swallow.
- Increasing difficulty communicating may use "word salad" (mixed up words), or be speechless. Non verbal communication may work best.
- May feel deep emotions and may scream, moan, or fail.
- Not recognizing you or others by name.
- Unable to control bowel or bladder
- Rigidity, immobility, jerks or seizures.
- Vulnerable to infections, especially pneumonia

# Communication Tips

Dementia damages pathways in the brain. Brain changes make it difficult for a person with dementia to say what they want and understand what others are saying. Your loved one may have trouble coming up with the right words or a name, or may invent new words.

At some point, they may repeat a question over and over. Because dementia changes communication skills gradually, a loved one's words may at times make little or no sense to you. He or she might also have trouble understanding your words. The resulting misunderstandings can fray nerves all around, making communication even more difficult.

## What you can do

- Be present. Let your loved one know you're listening and trying to understand. Keep your voice gentle. Hold the person's hand while you talk. Smile, nod, make appropriate eye contact.
- Show respect. Offer your loved one undivided attention, don't multi-task. Include your loved one in conversations, don't talk about them as if they weren't there.
- Avoid distractions. Background noise, like TVs or radios can compete for attention.
- Position yourself. Be close enough to be heard and seen clearly. Sit or stand at the same level, rather than standing over them.
- Get hearing checked regularly. If the person uses a hearing aid, check that it is working and inserted properly. When speaking, turn your face towards them and make sure your face is in the light so they can easily see your lip movements.
- Keep it simple. Use short sentences. Ask one question or offer one instruction at a time. It usually helps to use "positives" say "Let's go here" vs. "Don't go there." As the disease progresses, ask questions that require a yes or no answer.

- Allow time and be patient. Slow pace of speech slightly and allow time for the person to process and respond. Try to avoid interrupting. If you're feeling rushed or stressed, take some time to calm down.
- Focus on feelings. Listen for the meaning behind the words. Their tone or body language may provide clues. Respond to the emotions.
- Offer comfort. If a person with dementia is having trouble communicating, let them know it's OK. Offer hugs, or hold hands as appropriate.
- Use visual cues. Gestures or other visual cues can help promote better understanding than words alone. Rather than asking if your loved one needs to use the toilet, walk them to the toilet and point to it. Demonstrate a task first.
- Watch your tone and manner. Try to keep your voice gentle. No one likes to be talked down to or criticized. Try not to sound "bossy." Use friendly facial expressions and non verbal communication that conveys "calm." A person with dementia responds to others' moods, if you're upset, they may become upset too.
- Avoid quizzing and arguing. Instead of questioning or correcting your loved one, listen for the messages in what they're saying. Try to avoid arguing - no one will "win" and it will only lead to embarrassment, frustration or anger.

It's important to remember that your loved one isn't trying to be difficult - the disease has changed their brain. Try your best not to take communications and behaviors personally.

It's also important to know that these are offered as suggestions - we encourage you to **forgive yourself** when things don't go as well as you want them to. It can be helpful to talk with others in the same situation to get more ideas and support.

# Resources

## National Organization Resources

- Aging Life Care Association - private geriatric care management services:  
[www.aginglifecare.org](http://www.aginglifecare.org)
- Alzheimer's Association:  
[www.alz.org](http://www.alz.org) or 800-272-3900
- Alzheimer's Association/Global Resources:  
[www.alz.org/global](http://www.alz.org/global)
- Alzheimers.gov:  
[www.alzheimers.gov](http://www.alzheimers.gov)
- Eldercare Locator (Administration on Aging):  
[eldercare.acl.gov/Public/Index.aspx](http://eldercare.acl.gov/Public/Index.aspx) or 800-677-1116

## Florida Resources

- Florida Department of Health Alzheimer's Disease State Plan 2020:  
<https://elderaffairs.org/wp-content/uploads/alzheimers-disease-state-plan-2020.pdf>
- Florida End-of-Life Resources:  
[www.floridahealth.gov/provider-and-partner-resources/research/alzheimers\\_symposium/EndOfLifeResources.html](http://www.floridahealth.gov/provider-and-partner-resources/research/alzheimers_symposium/EndOfLifeResources.html)
- Honoring Choices, Florida - information about various end of life choices:  
<https://www.honoringchoicesfl.com/>
- The Florida Silver Alert - locating missing persons suffering from an irreversible deterioration of memory:  
<https://www.fdle.state.fl.us/AMBER-Plan/SilverAlert>

- ID Locator Service through Alzheimer's Community Care:  
[www.alzcare.org/wp-content/uploads/HANDOUT-ID-Locator-Flier-for-CGs-English-Revised-October-2022.pdf](http://www.alzcare.org/wp-content/uploads/HANDOUT-ID-Locator-Flier-for-CGs-English-Revised-October-2022.pdf)
- Florida Elder Affairs Dementia Care and Cure Initiative:  
<https://elderaffairs.org/programs-services/bureau-of-elder-rights/dementia-care-cure-initiative/>

## Palm Beach and Martin County Resources

- Dementia Specific Services and Education:  
<https://www.alzcare.org/>
- Program for All Inclusive Care of the Elderly:  
<https://morselife.org/pace/>
- Area Agency on Aging Palm Beach/Treasure Coast, Inc:  
<https://www.aapbtc.org/about-us>
- Collaborative effort between Alzheimer's Community Care and the Council on Aging of Martin County:  
<https://www.martincountyhugs.org/about-us/>

## Information and Documents

- At the Crossroads: Family Conversations about Alzheimer's, Dementia and Driving:  
[www.thehartford.com/resources/mature\\_market\\_excellence/crossroads\\_kit](http://www.thehartford.com/resources/mature_market_excellence/crossroads_kit)
- Caring for a Person with Alzheimer's Disease: Your Easy to Use Online Guide from the National Institute on Aging:  
[www.nia.nih.gov/alzheimers/publication/caring\\_person\\_alzheimers\\_disease/about\\_guide](http://www.nia.nih.gov/alzheimers/publication/caring_person_alzheimers_disease/about_guide)
- Communication: Tips for successful communication during all stages of Alzheimer's Disease:  
[www.alz.org/national/documents/brochure\\_communication.pdf](http://www.alz.org/national/documents/brochure_communication.pdf)
- Dementia and Driving Issues:  
[www.alz.org/care/alzheimers-dementia-and-driving.asp](http://www.alz.org/care/alzheimers-dementia-and-driving.asp)
- Home Safety for People with Alzheimer's Disease:  
[www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease/introduction](http://www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease/introduction)
- Living Well with MCI/Early Dementia:  
[www.actonalz.org/pdf/Living-Well.pdf](http://www.actonalz.org/pdf/Living-Well.pdf)
- Living with Alzheimer's Taking Action Workbook:  
[www.actonalz.org/pdf/Taking-Action.pdf](http://www.actonalz.org/pdf/Taking-Action.pdf)
- MedicAlert:  
[www.alz.org/care/dementia-medic-alert-safe-return.asp](http://www.alz.org/care/dementia-medic-alert-safe-return.asp)  
or 888-413-3768
- Living with Alzheimer's Take Action Notebook :  
<https://www.alz.org/getmedia/da9e2ce1-d73c-437a-be7c-d5761afd06e9/taking-action-workbook>

- Conversation Starter Kit for families and loved ones of people with alzheimer's disease or other forms of dementia:  
[www.theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf](http://www.theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf)
- Family Caregiver Alliance - Dementia, Caregiving, and Controlling Frustration:  
[www.caregiver.org/resource/dementia-caregiving-and-controlling-frustration](http://www.caregiver.org/resource/dementia-caregiving-and-controlling-frustration)
- Alzheimer's Disease Education and Referral Center, National Institute on Aging:  
[www.nia.nih.gov/health](http://www.nia.nih.gov/health)
- Medical Referral Form to report unsafe drivers by a physician:  
<https://www.flhsmv.gov/pdf/forms/72190.pdf>

### Resources for Dementia other than Alzheimer's

- The Association for Frontotemporal Degeneration:  
[www.theaftd.org](http://www.theaftd.org)
- Frontotemporal Disorders: Information for Patients, Families and Caregivers:  
<https://www.ninds.nih.gov/Disorders/All-Disorders/Frontotemporal-Dementia-Information-Page>
- Lewy Body Dementia Association:  
[www.lbda.org](http://www.lbda.org)



## Summary of Important Action Steps

- Obtain a medical assessment of memory loss/cognitive impairment and diagnosis for your loved one - this opens the door to necessary planning. This process should start with your health care practitioner, and may involve other specialists such as a Geriatrician, a Neurologist, and/or a Neuropsychologist
- Contact the Alzheimer's Association for information and support. Or contact Dementia Support Northwest (NW Washington)
- Contact your area's Community Living Connections (Area Agency on Aging/ Family Caregiver Support Program).
- Review the Dementia Legal Planning Toolkit
- Complete health care planning documents. Your loved one should have:
  - > A Health Care Directive (also called a "living will" or "advance directive" regarding treatment preferences); and
  - > A Durable Power of Attorney for Health Care, appointing a health care "agent."
- Complete a General Durable Power of Attorney document. In this document, your loved one appoints an "agent" to assist with financial and related matters.
- Contact the Dementia Legal Planning program if you have questions about completing power of attorney or health care/ advance directive forms.
- Complete an estate plan. Your loved one's estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- Consider Care Coordination or Case Management Services: "Guides" for the journey, they can assist with each step.

- Complete end-of-life planning and document how your loved one wants to live at the end of their life, including medical care wanted or not wanted, comfort measures, and palliative and hospice care.
- Discuss with loved one the issue of when to discontinue driving. If needed, enlist help of healthcare provider, a professional driving evaluation, or call the Alzheimer's Association for more ideas.
- Make sure your loved one either carries ID or wears MedicAlert jewelry.
- Request a home safety evaluation with a Physical or Occupational Therapist to make the home safer and home care tasks easier.
- If help with financing care is needed, contact your local Community Living Connections or Home and Community Services offices. Find these at [www.waclc.org/connect](http://www.waclc.org/connect)
- Have family meetings along the way to discuss what's happening, and how to support the person with memory loss and care partner. Important topics of discussion include:
  - > Encouraging a diagnosis; Discussing safety issues, such as driving and safe medication use
  - > Needing support with financial or legal planning Coordinating care at home
  - > Considering safe living situation and options
  - > Discussing ways to support the primary care partner/caregiver.
- Make and update a back up plan along the way to be used if something happens to you.
- Discuss and seek palliative care and hospice care.
- Talk to health care professional about establishing a Portable Orders for Life Sustaining Treatment (POLST) when appropriate.



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