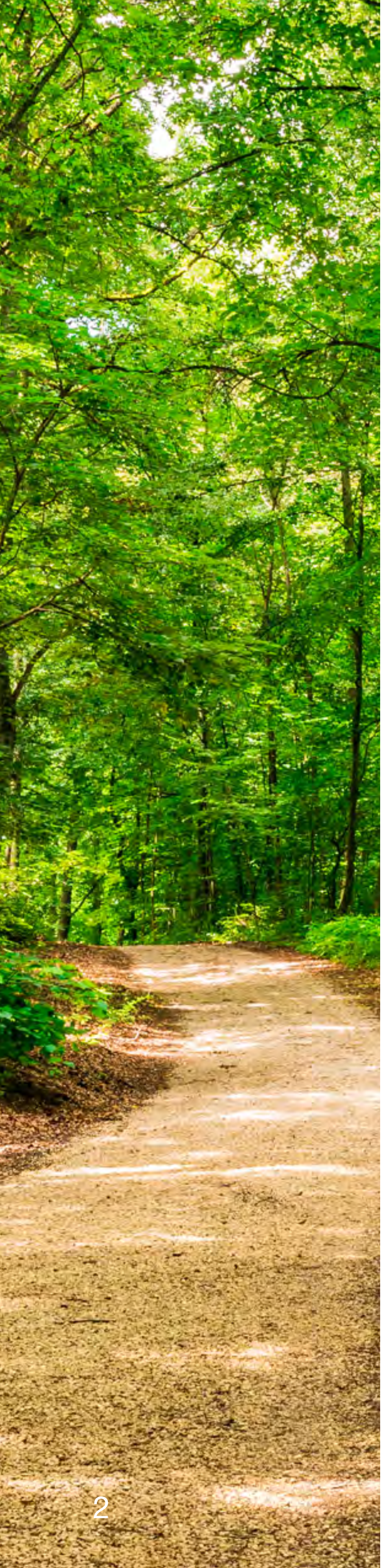
Oregon Dementia Road Map

A Guide for Family Caregivers and Care Partners

ADRC
Aging and Disability
Resource Connection
of OREGON

DHS
Oregon Department
of Human Services



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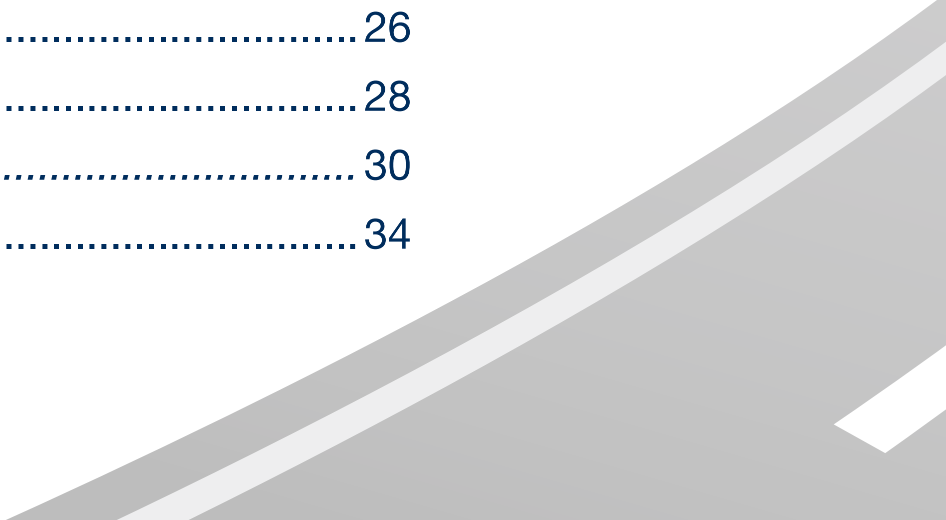
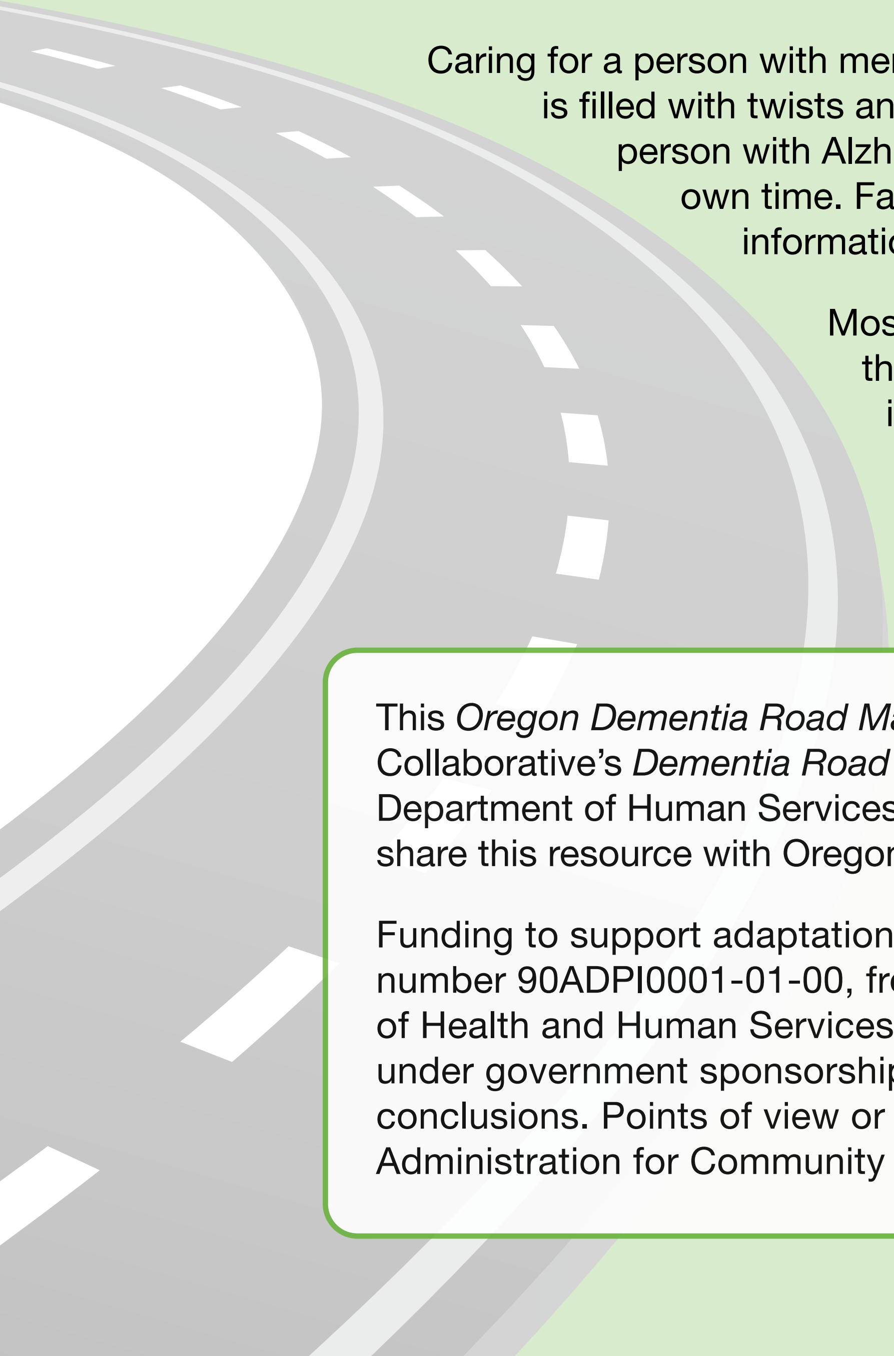


Overview

Are you concerned that your loved one may be experiencing dementia? If so, use this guide to learn more about their journey and how you can help.



Caring for a person with memory loss or dementia is a journey. It can last for many years and is filled with twists and turns. The journey is not a straight path through stages — each person with Alzheimer's or other 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 "road map." This document is designed to be just that.

It provides a look at the big picture and the road ahead — and offers direction and tips about what to expect, what decisions lie ahead and what steps to take.

This *Oregon Dementia Road Map* is adapted from Washington state's Dementia Action Collaborative's *Dementia Road Map: A Guide for Family and Care Partners*. Oregon Department of Human Services is grateful to Washington state for allowing us to adapt and share this resource with Oregonians. Many thanks to our neighbors to the north!

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Dementia Road Map Quick Guide

For Family Caregivers and Care Partners

Below are some questions you may be asking at different stages of the dementia journey. Go to the page number under each stage for more information.

Wondering and worried

Page 8

- 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)

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

Early-stage dementia

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

Mid-stage dementia

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- What can I do to make the home safer?
- What do I do if my loved one won't stop driving?
- Where do I 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?

Late-stage dementia

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- What can I do to promote quality of life?
- What kind of care is best for my loved one?
- What medical care does my loved one and I want at the end of my loved one's life?

Introduction

Guides for the journey

We whole-heartedly recommend that every care partner contact these key agencies in their community to guide and support them over time:

Oregon's Aging and Disability Resource Connection (ADRC) is a trusted statewide network that helps connect people to services and resources in each community, and offers options counseling to help make decisions based on personal needs. Area Agencies on Aging (AAAs), which are part of the ADRC, help older adults and their families find specialized information, supports and service options in their area. AAAs also offer the Family Caregiver Support Program that helps family members assist a loved one with dementia or other conditions. Visit **www.ADRCofOregon.org** or call **855-ORE-ADRC** (673-2372) to find your Area Agency on Aging and more information.

The Alzheimer's Association® has free literature on all things dementia available in English and Spanish. They also have a 24/7 Helpline (in a caller's preferred language through a translation service), with the latest information on brain health, available medications for people with dementia, support groups, trainings and care consultation to help with decision making. Visit **www.alz.org/orswwa** or call **800-272-3900**.

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 a part of 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 on other forms of dementia, see page 33.

Terminology

Throughout this document, a variety of terms are used:

Loved one —
the person with memory loss or dementia.

Care partner or family caregiver —
the person providing most of the support or care for their loved one.

Other friends and family —
people other than the primary care partner who are concerned for their loved one with dementia and may provide help.

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 could you expect at this stage?

You may 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 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.

☑ Action steps — *The following steps are important at this point:*

☐ **Obtain a medical assessment** to find out what may be causing the problems. For more information, see the “Concerned About Dementia?” fact sheet at **http://www.oregonspado.org/resources**.

☐ **Complete health care and financial planning documents.** Your loved one should have an advance directive (also called a “health care directive” or “living will”) regarding treatment preferences.

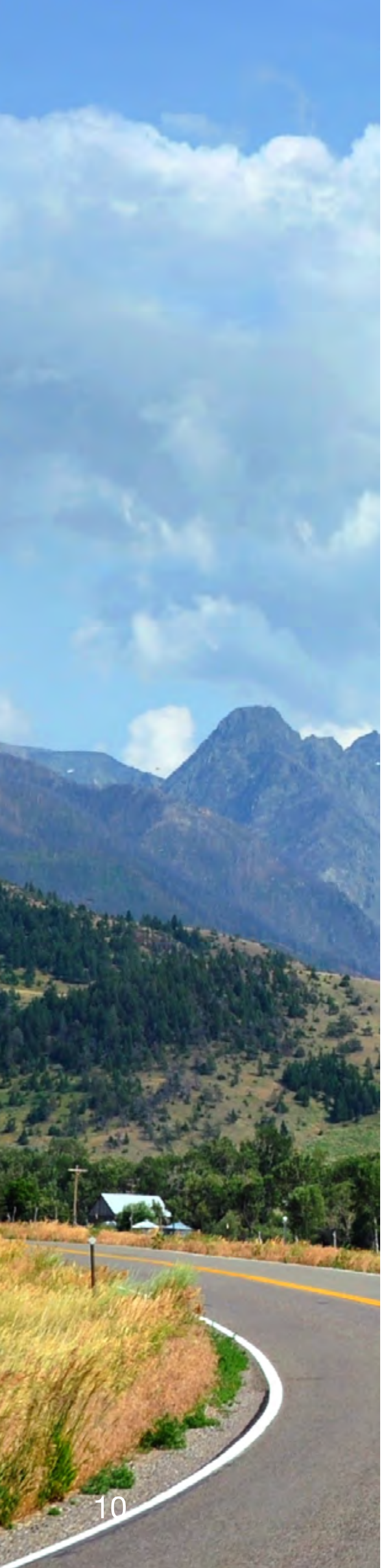
What you can do

- Learn about normal changes with aging and those that may suggest a need for a medical checkup. See the "10 warning signs" on page 27.
- Keep track of changes in memory or behavior. If your loved one doesn't bring them up, find a good time and way to discuss them.
- Ask your loved one to have a complete medical checkup. Memory and thinking changes may be caused by something that could be treated or reversed. In any case, it's best to have a diagnosis.
- Ask trusted family or friends to encourage a medical checkup if your loved one resists having one.
- If your loved one is covered by Medicare, ask their health care professional for the Medicare Annual Wellness Visit, which includes cognitive impairment testing. You can share a letter or talk with the professional about what you've noticed.
- Most primary care professionals can diagnose dementia. If you aren't comfortable with your loved one's current health care provider or want a specialist, contact the Alzheimer's Association for a list of providers in your area.
- If you think your loved one has hearing loss, get it checked and addressed. Hearing loss can make it harder to communicate and lead to misunderstandings and social isolation.
- Make sure you and your loved one:
  - » Stay active and engaged in social groups, arts and other activities of interest
  - » Eat fresh fruits and vegetables
  - » Are physically active.
- Prioritize completing legal, financial and advance care planning. This planning is important for all adults, and even more so for those who experience changes in memory or thinking abilities. Complete this planning while your loved one has the ability to do so.

☐ **Complete a general durable power of attorney document** to appoint an agent to assist with financial and related matters.

☐ **Complete an estate plan** that 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 I do to promote my loved one's well-being?

What could you expect at this stage?

Your loved one:

- Is still independent but may have difficulty paying bills, preparing meals, shopping, driving
- May forget details, display less ambition, have emotions that go up and down, and be more reliant on you
- May find particular success in completing familiar routines and habits.

☑ **Action steps** — *In addition to the action steps on pages 8–9, do the following:*

☐ **If your loved one has not yet had a medical assessment,** contact their health care professional, a geriatrician, a neurologist or a neuropsychologist. For more information, see "Concerned About Dementia?" fact sheet at **http://www.oregonspado.org/resources**.

☐ **Discuss with your loved one** the issue of when to discontinue driving. See resources on page 31.

You may:

- Feel irritation with your loved one's differing abilities
- Also feel compassion for your 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

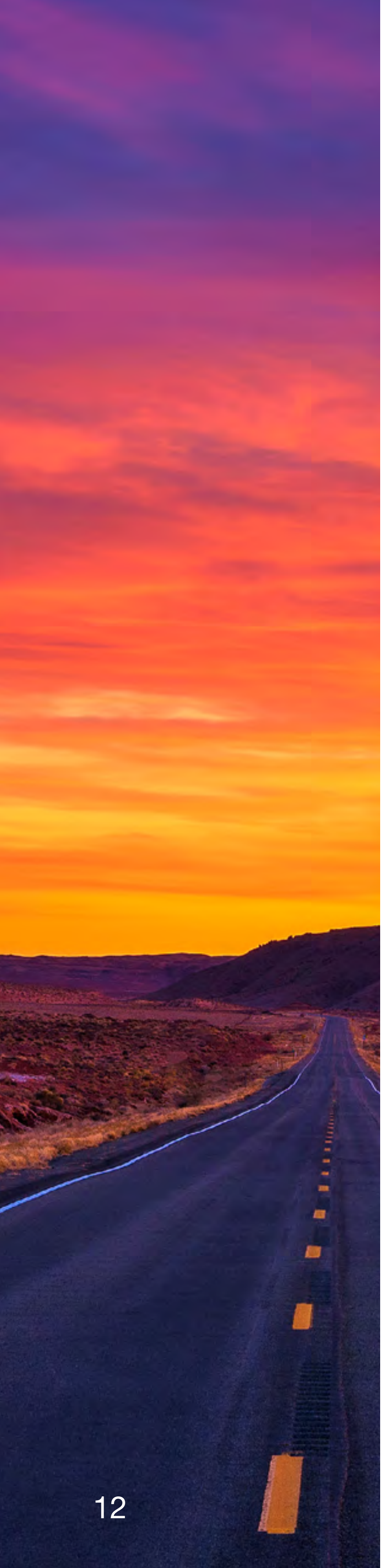
- If your loved one has not yet been evaluated, ask their health care professional for the Medicare Annual Wellness Visit. It includes detection of cognitive impairment along with other screenings.
- Ask your loved one if you can attend and participate in their medical appointments.
- Inquire about lifestyle changes that may be helpful to overall wellness and functioning.
- Learn more about mild cognitive impairment (MCI).
- Tell your own health care provider that you are caring for a loved one with cognitive impairment so your provider can be aware of your potential health-related risks.
- Consider keeping a notebook about your loved one's changes and needs.
- Instead of thinking that your loved one should just "try harder," remind yourself that they are doing the best they can.
- 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. For tips, go to **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 skills they have had for many years such as playing the piano, singing, typing, crafts or speaking a second language.
- Learn more about how to live well with MCI or Alzheimer's disease. See resources on pages 30–32.

☐ **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 checkup 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 I help my loved one stay active and connected?
- Should my loved one still be driving?
- Is my loved one's legal paperwork in order?

What could you expect at this stage?

Your loved one may:

- Find it hard to accomplish some activities
- Have trouble with time or sequence of events
- Forget names of familiar people and things
- Have decreased performance in work or social situations
- Have trouble multi-tasking
- Take more time to process information
- Write reminders and lose them
- Have increased preferences for familiar things
- Have mild mood and/or personality changes
- Feel sorrow, suspicion, anger, frustration
- Show increasing indifference to normal courtesies of life
- Have more trouble driving safely.

At the same time, you may find some kinds of memory work quite well. They will likely remember stories from long ago and how to do familiar things (such as playing an instrument). They may focus more on the present moment, enjoy a sense of humor and grow in creativity.

You may:

- Feel optimism and/or an early sense of loss
- Need to remind and supervise more
- Want to ask for help around the home such as housekeeping, errands, laundry or yard care
- Be impressed by your loved one's ability to adapt and grow in the midst of challenges.

What you can do

- Be an advocate for the right diagnosis and best health care. If needed, find a health care professional that will work with you and your loved one.
- Learn about the disease and how to communicate with your loved one. See "Communication tips" on pages 28–29.
- Put safety measures in place before they're needed related to falls, wandering, power tools, guns, etc. Find safety resources on page 31.
- Embrace the good days and prepare yourself for the stormy ones.
- Make your life a no guilt zone.
- Keep up your health and wellness appointments.
- Try to get a good night's sleep every night.
- Get support from others with similar experiences (e.g., early memory loss support group) or call the Alzheimer's Association 24/7 Helpline.
- Explore how your loved one wants to live at the end of their life. See resource list on page 32 for "Your Conversation Starter Kit For Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia."

You may be thinking, **"I'm tired, afraid, and I feel alone with this."**

You are not alone! Just take one step at a time. Contact one or more of the organizations listed below:

- **Aging and Disability Resource Connection (ADRC) of Oregon** at **855-ORE-ADRC** (673-2372) or **www.ADRCofOregon.org**
- **Alzheimer's Association Oregon & Southwest Washington** at **800-272-3900** or **www.alz.org/orswwa**

To help your loved one

- Provide “Taking Action – A Personal and Practical Guide for Persons with Mild Cognitive Impairment (MCI) and Early Alzheimer’s Disease.” Find this in the resource list on page 31.
- Go along on medical appointments if your loved one agrees. If they do not want this, try calling the health care provider ahead of appointments to share concerns.
- Create and stick to simple routines.
- Monitor that all medications are taken properly.
- Help them 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.

Action steps — *In addition to the action steps on pages 8–9 and 10–11, do the following:*

☐ **If your loved one is still driving, review together the booklet** “At the Crossroads: Family Conversations about Alzheimer’s Disease, Dementia & Driving” on the resource list, on page 31.

☐ **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 sure your loved one** either carries ID or wears MedicAlert® jewelry.

- Ask your loved one to 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.
- Look for ways to modify your loved one's favorite activities rather than give them up.
- Help family and friends understand how to communicate and interact. If needed, share what they like to do, how to start a conversation, the need to avoid correcting and arguing.
- Consider ways to protect yourself and your loved one from financial missteps and exploitation. For example, you may remove your loved one's credit cards (or lower credit limits) and other key wallet documents.

Services to consider

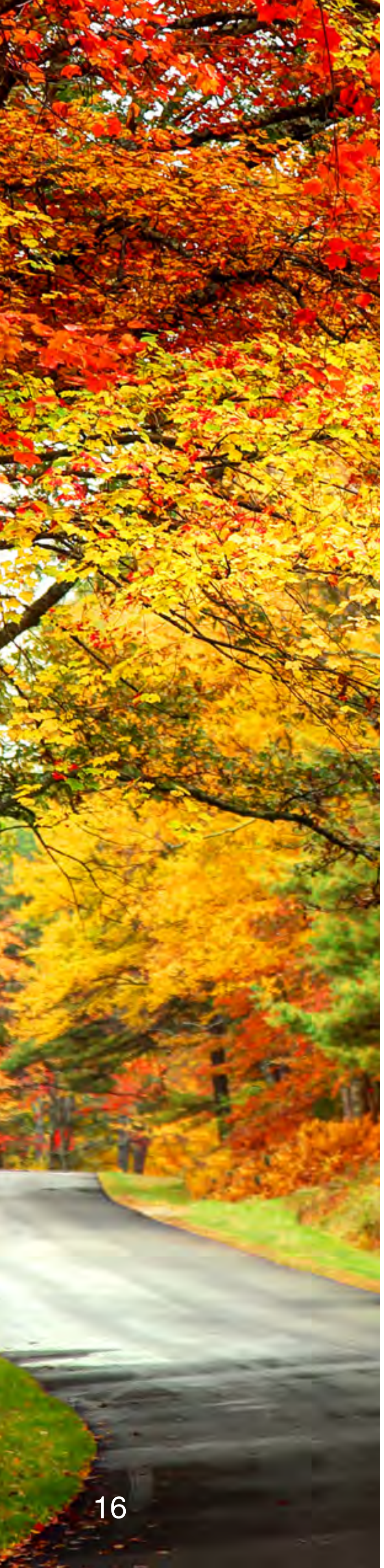
- In-person or online educational workshops offered by Oregon Care Partners: **www.OregonCarePartners.com**
- Powerful Tools for Caregivers or other care partner classes offered through the ADRC
- Online connections such as the Alzheimer's Navigator, ALZConnected online community or e-learning modules offered through the Alzheimer's Association and/or the "Alzheimer's Reading Room"
- The Alzheimer's Association in collaboration with MedicAlert® uses a community support network, including the police, to locate your loved one in case they wander or have a medical emergency. Visit **www.alz.org/medicalert** to learn more. You can also look into locator aids that use active GPS capability (real-time tracker).

☐ **Make a backup plan** to be used if something happens to you.

☐ **Discuss with your loved one their wishes** for end-of-life care, and document these as decisions are made.

☐ **In addition to an advance directive and general durable power of attorney, consider** completing the following additional health planning form:

An Oregon Physician Orders for Life-Sustaining Treatment (POLST) — a medical order completed with your health care provider to honor your loved one's wishes for treatment as they move from one health care setting to another.
Go to **https://oregonpolst.org.**



Mid-stage dementia

You may be wondering ...

- What can I do to make the home safer?
- What do I do if my loved one won't stop driving?
- Where do I get help 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 could you expect at this stage?

Your loved one may:

- Exhibit more obvious confusion
- Have increasing needs for care and supervision
- 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
- Resist bathing or other personal care
- Have episodes of incontinence
- Have abilities that vary from one day to the next
- Complain of neglect or blame others when things go wrong

- Lack judgment and develop the following behaviors:
  - » Trouble sleeping
  - » Apathy, passivity
  - » Irritability, aggressive talk and actions
  - » Clinging (following you around)
  - » Repetitive questions
  - » Wandering
  - » Delusions (false beliefs) or hallucinations (seeing/hearing things that aren't there)
- Have more problems with balance (increasing the risk for falls)
- Not be able to contribute to family life in traditional ways
- Be increasingly sensitive to the care partner's mood and behavior.

At the same time, they may be increasingly present in the moment, continue to use their five senses to enjoy the world around them, discover new ways of communicating (nonverbal, touch) and be quite creative.

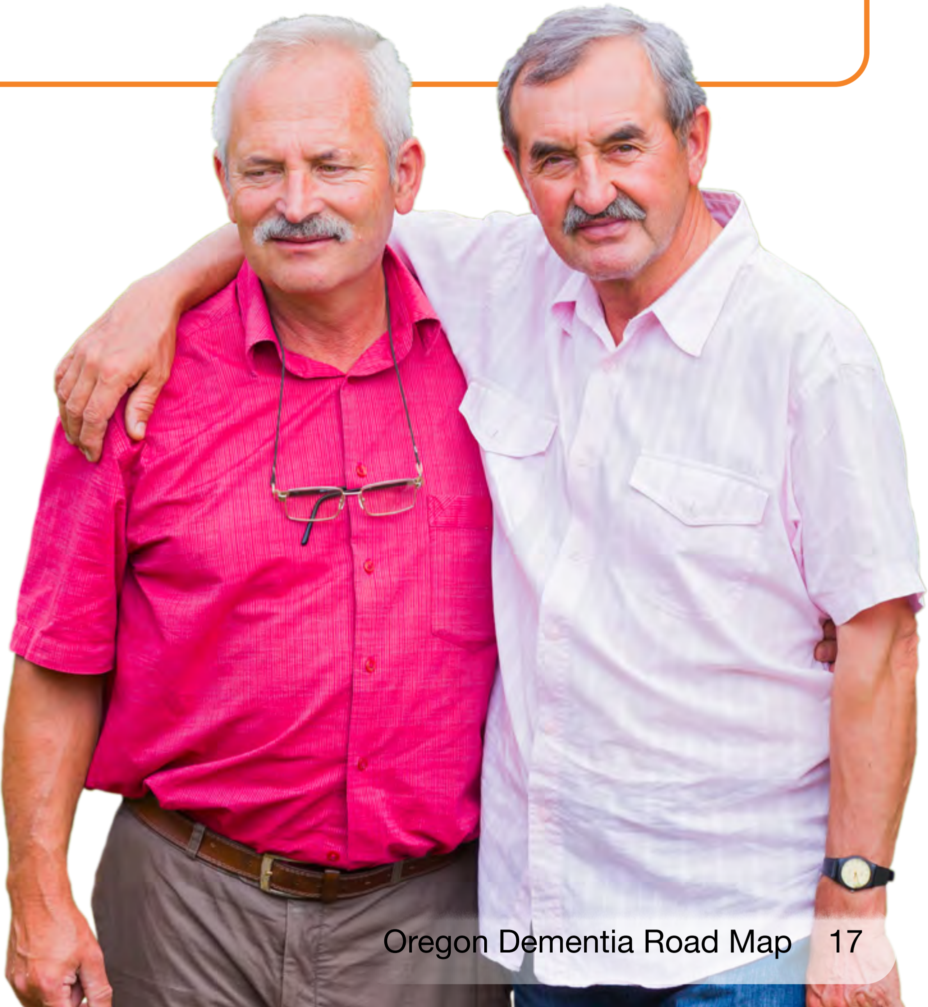
You may:

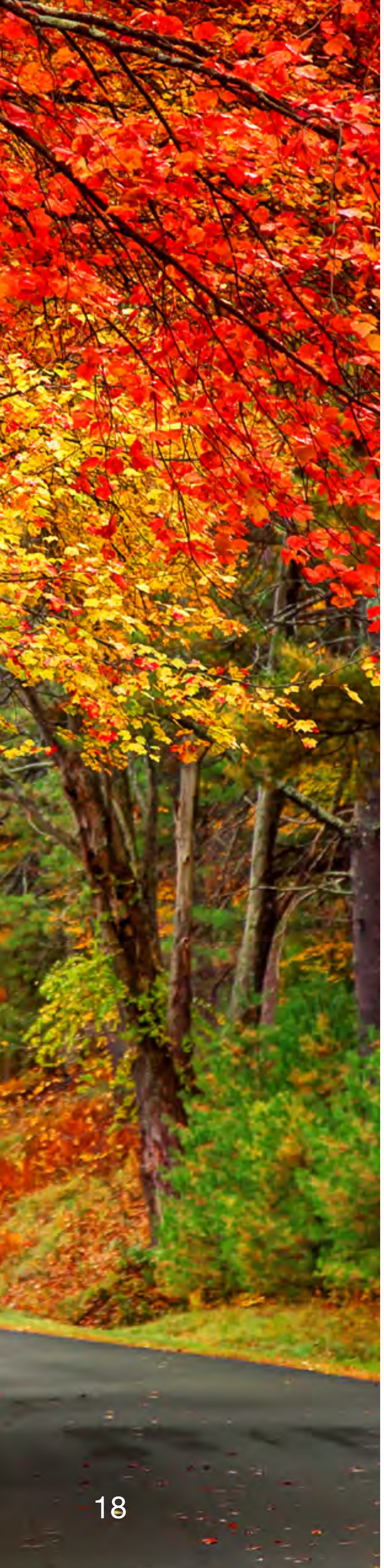
- Feel tired, stressed, lonely, isolated, angry or irritable
- Be wondering if you need assistance, or how long you can do this
- Notice that other friends and family are wondering how to help, sometimes wanting to take over the care.

You may be thinking, **"I need assistance. I can't do this anymore."**

Find out more about the services that may be available at no cost or low cost in your area. Start here:

- **ADRC of Oregon** at **855-ORE-ADRC** (673-2372) or **www.ADRCofOregon.org**
- **Alzheimer's Association** at **800-272-3900** or **www.alz.org/orswwa**





What you can do

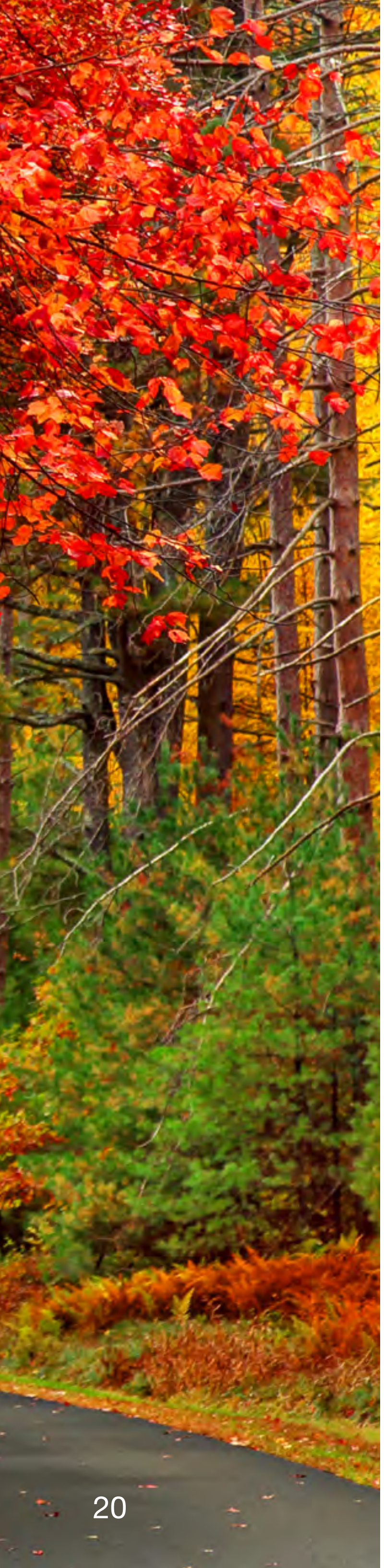
- At this stage, you will need the following kinds of support:
  - Daily relief from care tasks (also known as respite care)
  - A network of caring friends and family
  - Time to manage your own self-care.
- Establish or maintain routines for you and your loved one.
- Try not to mistake your loved one’s moodiness for rudeness.
- Practice not taking behaviors personally — it’s the disease.
- Ask for help with taking care of the home or providing care.
- If you get unwanted opinions or criticisms, recognize that others may be trying to help. Try to work out a plan for them to assist in some way. Remember, you are doing the best you can.
- Attend a support group.
- Vent as needed with trusted friends or other care partners.
- Take safety precautions related to falls, wandering, medication use, harmful cleaning products, guns, power tools, etc.
- If your loved one is still driving, enlist their health care provider’s help to get them to stop. Call the Alzheimer’s Association for additional ideas.
- Look into support and service options to help maintain your loved one’s current living arrangement, such as in-home care or adult day services.
- Investigate residential care options in your area in case they will be needed. These might include adult foster homes, assisted living or nursing homes. Look into their costs and take tours to prepare if you need to make a quick decision.

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 (**www.alz.org**) or **24/7 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 them into smaller steps. Allow more time for your loved one to accomplish them.
- Reminisce. Look at old photos 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 Physician 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" at **www.alz.org/care** to find helpful tips on daily care such as activities, providing personal care and managing incontinence.

Services to consider

- Education workshops or conferences for care partner
- Technology to assist with a variety of tasks — reminders, cameras, chimes to alert if an exterior door opens, etc.
- Adult day services that offer your loved one activity, exercise and socialization and provide you with some time for yourself
- In-home care to assist with bathing, dressing, getting ready in the morning or evening, other personal care tasks and routines
- Counseling to handle your own grief, depression and anger, and to get emotional support



Services to consider *(continued)*

- If you haven’t looked into or used yet:
    - » Powerful Tools for Caregivers and other care partner programs offered through the ADRC
    - » Support groups
    - » Respite care (in or out of the home)
    - » Consultants who specialize in caregiving issues and can assist with behaviors
    - » MedicAlert® or GPS locator program.
- To inquire about local education and support services mentioned above, contact your local Family Caregiver Support Program at **www.ADRCofOregon.org**.

Want to learn more about residential care options?

In addition to services that can help a person with dementia stay at home, there are many different types of homes or facilities that provide long-term care. Options counseling offered by the ADRC can provide information on available services and help make decisions based on your personal situation. Residential care options in Oregon include adult foster homes, assisted living and residential care facilities, and nursing homes. To find out more about what’s available in your area, go to **www.ADRCofOregon.org/consite/explore-in-a-facility.php**.

Action steps — *In addition to the action steps on pages 8–9, 10–11 and 14–15, do the following:*

☐ **Request a home safety evaluation** with a physical or occupational therapist to make the home safer and home care tasks easier.

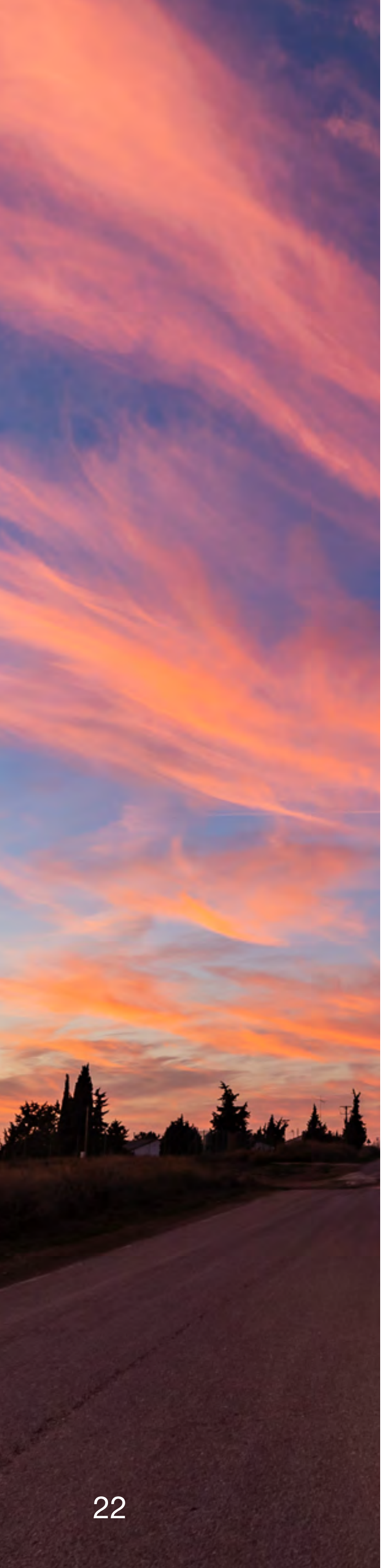
☐ **Have a family meeting** to discuss what’s happening now and ways to support your loved one and you. Talk about any next steps as care needs increase

> “The Powerful Tools for Caregivers class was a lifesaver for me. The class helped me to take time for myself and encouraged me to be more positive about the situation I am in at present.”
>
> — *Family caregiver from Pendleton*

☐ **Update your backup plan** to be used if something happens to you.

☐ **If help with financing care is needed,** contact the ADRC to explore options.

☐ **Complete end-of-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 I do to promote quality of life?
- What kind of care is best for my loved one?
- What medical care does my loved one and I want at the end of my loved one’s life?

What could you expect at this stage?

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

Your loved one 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 flail
- Be vulnerable to infections, especially pneumonia.

At the same time, you may notice 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.

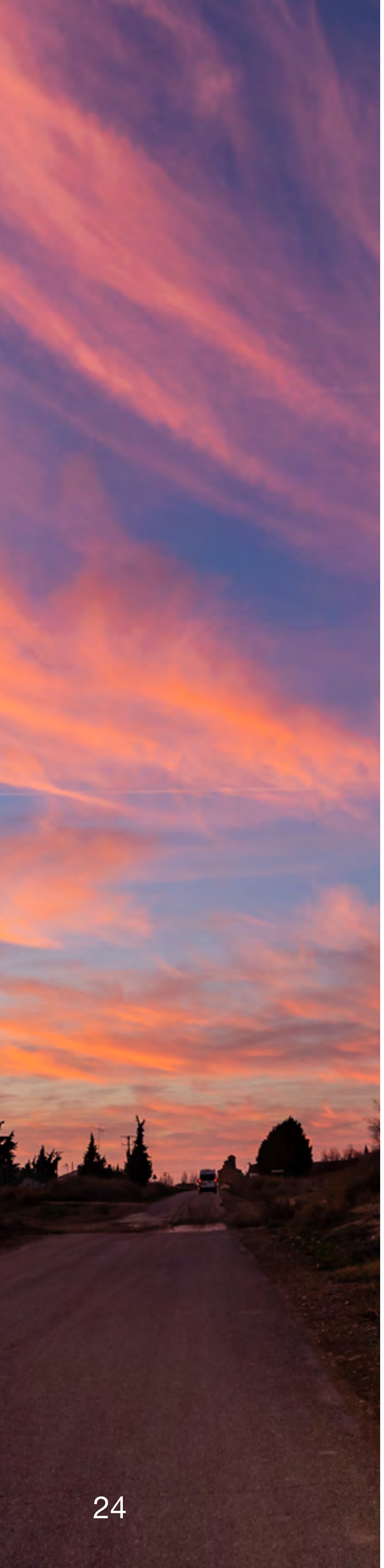
You may:

- 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 end-of-life preferences and plans that have already been made.

> **"My dad doesn't really know his great-grandson, and at two years old, my grandson doesn't really know his great-grandpa. But they feel the love and connection. The love and feelings are always there even when the memory isn't."**
>
> — *Sally D., family caregiver from Dallas*



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.
- Your loved one may not be verbal or ambulatory but still appreciates kind words, loving hugs and comfort.

Services to consider

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

Action steps — *In addition to the action steps on pages 8–9, 10–11, 14–15 and 20–21, do the following:*

☐ **Discuss and plan for palliative and hospice care** with your loved one's health care provider.

You may feel like this:
"I'm worn out, and I am grieving."

- Find support from others in a similar situation, a care coordinator, a counselor, the Alzheimer's Association or your local ADRC Family Caregiver Support Program:
  - **ADRC of Oregon** is at **855-ORE-ADRC** (673-2372)
  - **Alzheimer's Association** is at **800-272-3900** or **www.alz.org/orswwa.**

Common symptoms in the progression of dementia

Early–stage dementia

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

Mid-stage dementia

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

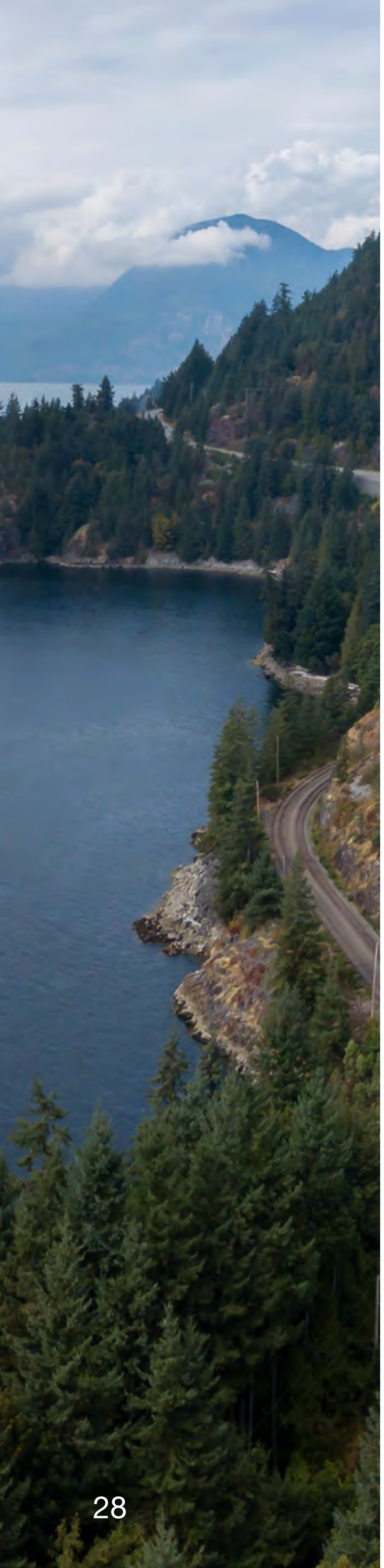
Late-stage dementia

- Dependent for personal care activities
- Not recognizing you or others by name (This does not mean they don't know or feel who you are.)
- Changes in physical abilities including 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.)
- Frequent or total incontinence
- Rigidity, immobility, jerks or seizures
- Feeling deep emotions and may scream, moan or flail
- Vulnerability to infections, especially pneumonia

10 warning signs of Alzheimer's disease

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 other dementias, go to **https://www.nia.nih.gov/health/alzheimers/related-dementias.**



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 they may invent new words. At some point, they may repeat a question over and over. Because dementia gradually changes communication skills, 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.

You can expect that, over time, a person living with dementia may struggle to organize their message, lose their train of thought or speak less often.

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, such as from 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.

> **"Because the disease is progressive, change is constant. You are both adjusting to a new reality every day. Nothing in life has prepared either one of you for it. Cut yourself and your loved one as much slack as you can as often as you can. Remember empathy. Remember compassion."**
>
> *— Susan J., family caregiver from Salem*

Get your loved one’s hearing checked regularly.

If the person uses a hearing aid, check that it is working and inserted properly. When speaking, turn your face toward 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. For example, 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 their hand 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 go. It can be helpful to talk with others in the same situation to get more ideas and support. The Alzheimer’s Association or your local ADRC will know of these opportunities. **Reach out today!**

Resources

Organizations

Aging and Disability Resource Connection (ADRC)

www.ADRCofOregon.org
855-ORE-ADRC (673-2372)

ADRC Alzheimer's disease and related dementias

www.ADRCofOregon.org/consite/explore-alzheimers-disease-and-related-dementias.php

Alzheimer's Association

www.alz.org
800-272-3900

Alzheimer's Association Oregon & Southwest Washington

www.alz.org/orswwa
800-272-3900

Alzheimers.gov

www.alzheimers.gov

Oregon Care Partners

https://oregoncarepartners.com
800-930-6851

Caregiver resources

Alzheimer's Caregiving
www.nia.nih.gov/health/alzheimers/caregiving

At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia & Driving
http://hartfordauto.thehartford.com/UI/Downloads/Crossroads.pdf

Communication: Tips for Successful Communication During All Stages of Alzheimer's Disease
www.alz.org/national/documents/brochure_communication.pdf

Dementia and Driving — information on signs of unsafe driving, planning ahead and talking about driving concerns
www.alz.org/care/alzheimers-dementia-and-driving.asp

Home Safety and Alzheimer's Disease
https://www.nia.nih.gov/health/home-safety-and-alzheimers-disease

I Have Alzheimer's
https://www.alz.org/help-support/i-have-alz

Living Well: A Guide for Persons with Mild Cognitive Impairment & Early Dementia
www.actonalz.org/pdf/Living-Well.pdf

MedicAlert®
www.alz.org/medicalert | 800-ID-ALERT (800-432-5378)

Resources on the Dementia Diagnosis
www.oregonspado.org/resource

Taking Action — A Personal and Practical Guide for Persons with Mild Cognitive Impairment (MCI) and Early Alzheimer's Disease
www.actonalz.org/pdf/Taking-Action.pdf

When to Stop Driving — Oregon Department of Transportation offers guidance on when to stop driving
https://www.oregon.gov/ODOT/DMV/50plus/Pages/50plus_stop_driving.aspx

Resources *(continued)*

Legal and advance care planning

Your Conversation Starter Kit For Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia — To help people with dementia have conversations with their family members about how they want to live at the end of their lives: the care they want and the care they don't want. It is designed to be used in the early stages of dementia.

https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf

Planning for Your Future: A Toolkit for Long-term Services and Supports — Provides information and planning tools to help individuals and families plan for long-term care needs

www.ADRCofOregon.org/consite/plan.php

Options in Oregon to Help Another Person Make Decisions — A brief guide on legal and other tools available to help with guardianship, conservatorship and other options in Oregon

https://www.oregon.gov/DHS/SENIORS-DISABILITIES/SUA/Documents/options-oregon-help-person-make-decisions.pdf

Compassion and Choices — Resources and tools for helping plan end-of-life care decisions

https://compassionandchoices.org/in-your-state/oregon

Oregon POLST — Physician Orders for Life-Sustaining Treatment — A voluntary form completed by a health care provider to clarify treatment decisions late in life

https://oregonpolst.org

Resources on other dementias

Alzheimer's Disease & Related Dementias, National Institute on Aging

https://www.nia.nih.gov/health/alzheimers/related-dementias

Alzheimer's Association, Types of Dementia

www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia

The Association for Frontotemporal Degeneration

www.theaftd.org

Frontotemporal Disorders: Information for Patients, Families and Caregivers

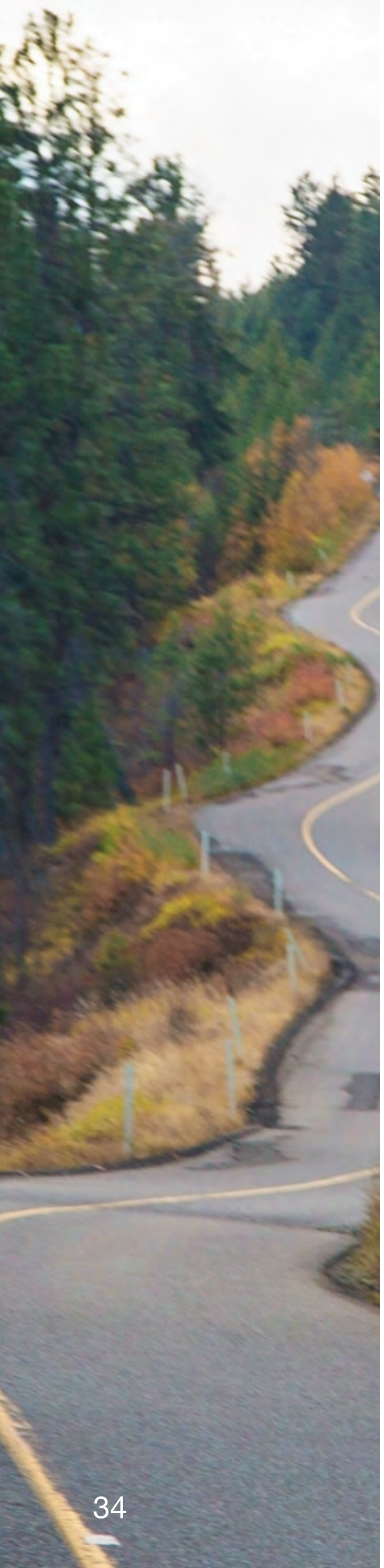
https://order.nia.nih.gov/sites/default/files/2017-07/ADEAR_FTD_508.pdf

Lewy Body Dementia Association

www.lbda.org

Lewy Body Dementia — Information for Patients, Families and Professionals

https://catalog.ninds.nih.gov/ninds/product/Lewy-Body-Dementia-Information-for-Patients-Families-and-Professionals/18-AG-7907



☑ Action steps summary

☐ Contact these key agencies in your community to guide and support you over time:

- ADRC of Oregon at **855-ORE-ADRC** (673-2372) or **www.ADRCofOregon.org**
- Alzheimer's Association at **800-272-3900** or **www.alz.org/orswwa**.

☐ Obtain a medical assessment of memory loss/cognitive impairment and diagnosis for your loved one. This opens the door to necessary planning. The 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 ADRC of Oregon (Area Agency on Aging/Family Caregiver Support Program).

☐ Complete health care planning documents. Your loved one should have:

- An advance directive (also called a "health care directive" or "living will" regarding treatment preferences), and
- An Oregon POLST (a medical order completed with your health care provider). Go to **https://oregonpolst.org**.

☐ 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.

☐ 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 your loved one the issue of when to discontinue driving. If needed, enlist a health care provider's help or get a professional driving evaluation. You can also call the Alzheimer's Association for more ideas.

☐ Make sure your loved one either carries ID or wears MedicAlert® jewelry.

☐ If you need help with financing care, contact the ADRC for options.

☐ Have family meetings along the way to discuss what's happening, and how to support the person with memory loss and their 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 or care partner.

☐ Request a home safety evaluation with a physical or occupational therapist to make the home safer and home care tasks easier.

☐ Make and update a backup plan along the way to be used if something happens to you.

☐ Discuss and seek palliative care and hospice care.

If you need this document in another language, large print or other format, contact the Aging and Disability Resource Connection (ADRC) at 503-945-6237 or email ADRC.Info@dhsoha.state.or.us. We accept all relay calls or you can dial 711.