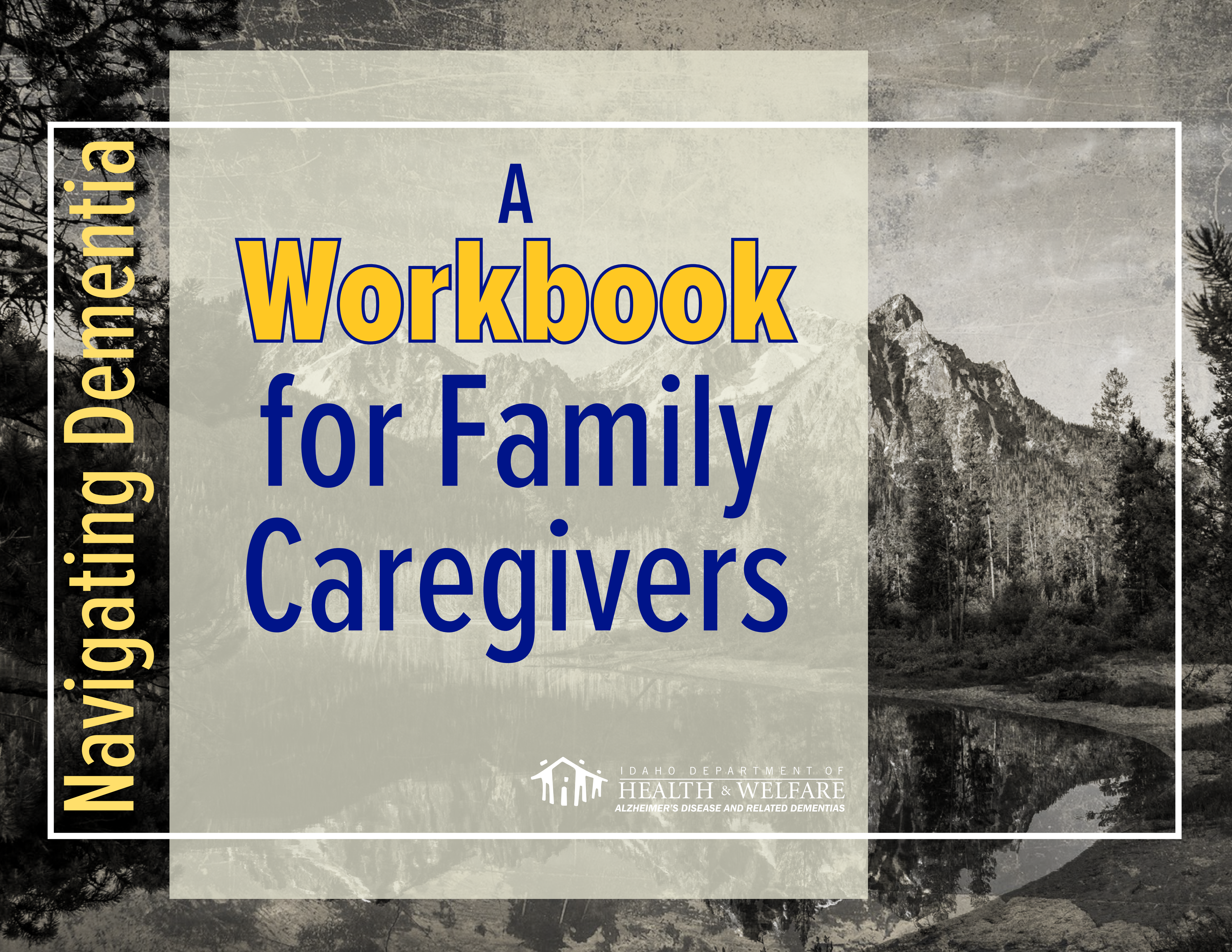


## Navigating Dementia

# A Workbook for Family Caregivers

IDAHO DEPARTMENT OF
HEALTH & WELFARE
ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

# Navigating Dementia: A Workbook for Family Caregivers

ADRD
Idaho Alzheimer's Disease &
Related Dementias Alliance

IDAHO DEPARTMENT OF
HEALTH & WELFARE
ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

This caregiver workbook was made possible with combined funding from the State of Idaho and the Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services (HHS); as part of a financial assistance award (No.NU58DP007507) totaling $450,000 with 50 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government. May 2024.

# Table of Contents

# Dementia Workbook Overview

## Taking Care of You

- What is my value as a caregiver?
- Why should I take time to build my care map now?
- How do I let others know what I'm experiencing and that I don't want to do it alone?

## Wondering & Worried

- Is everything ok?
- Should my care recipient be checked by a healthcare professional?
- What if my care recipient won't go to a healthcare professional?

## Mild Cognitive Impairment (MCI)

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

## Early-Stage Dementia

- Are there any medications, treatments, or lifestyle changes that could help my care recipient's memory and thinking?
- How can we help our care recipient stay active and connected?

- Should my care recipient 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 care recipient 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 care recipient?
- What do we want in terms of medical care at the end of our care recipient's life?

**If at any time you feel that you are overwhelmed, please reach out to friends, family, faith community, the 24/7 Helpline through the Alzheimer's Association, or the 988 Crisis Line for help and support. You do not have to do this alone.**

# Dementia Workbook for Idaho Caregivers

# Dementia Workbook for Idaho Caregivers

Caring for a person with memory loss or dementia is a journey, one that 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 dementias 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 they would welcome some type of “Workbook.” This document, adopted from the Washington State Dementia Action Collaborative’s dementia road map, 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.

Remember this is a Workbook to help guide you through your caregiving journey and like most journeys this one **does not have to be completed in a day or even in a month.** The steps can be **accomplished over time**, be strategic about how you go about tackling the steps presented to you. You need to **preserve your energy** and honor that you too are going through a major life changing experience.

## WORRIED ABOUT MEMORY LOSS IN A CARE RECIPIENT?

If you are worried about your care recipient’s forgetfulness, feel it is getting worse, or the memory problems are starting to interfere with everyday life, it is time to talk to a healthcare professional.

***Remember: Confusion and memory loss are NOT a normal part of aging.***

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 dementias, such as normal pressure hydrocephalus, thyroid problems, or a vitamin deficiency, are treatable and reversible. Certain medications and urinary tract infections can cause delirium which may look like dementia and should be addressed right away. Even if it turns out to be a mild cognitive (mental processes) impairment or a type of dementia, it is best to get a diagnosis and help early in the disease process.
- A healthcare professional can provide better clinical care for all medical conditions with a diagnosis, when they understand what is happening.

You, your care recipient, 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.

**Website Reference**
Throughout this document, resources referenced have a superscript number assigned to them following the name of the resource or website. To find the URL of the website associated with that resource, please find the assigned superscript number of the resource you are looking for on the Website Reference on page 73.

Although there are stages to dementia, not all stages are the same. Use the tabs to find the section that fits your situation, knowing you may need to look in other sections for additional information. One section you should not skip is the "Taking Care of You" section.

## GUIDES FOR THE JOURNEY

For every caregiver, we whole-heartedly recommend contacting at least three agencies in your community to guide and support you over time:

- Area Agencies on Aging (AAAs)[1] 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 care recipient with dementia or other conditions. Visit the provided link or call 208-334-3833 to contact the Idaho Commission on Aging and locate the Area Agency on Aging that serves your community.
- 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.
    - Greater Idaho Chapter[2] call 208-206-0041.
    - Washington State Chapter[3] (**serves North Idaho**) call 800-272-3900.
- The Idaho Community Care Program (I-CCP) 208-898-9626 was developed by the Idaho Commission on Aging, the state unit on aging, and provides support

to individuals caring for a person with memory loss or dementia; support and services include:

  - Connection to resources in the community.
  - Referrals for services including caregiver education, respite, and support groups.
  - Coordination of caregiver supports.

- If your care recipient belongs to the disability community or the LGBTQ community, it is important to know that although the three agencies listed above should be able to help, you might also want to connect with specialized resources. The Idaho Center for Independent Living that serves your area can be found here silc.idaho.gov/idaho-centers-for-independent-living. Sage is a national organization that advocates and provides information for LGBTQ elders and can be found here www.sageusa.org.

Another type of "guide," available in some areas of Idaho, is a private geriatric care manager. They may be found through the Aging Life Care Association[4] for a fee.

## 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.

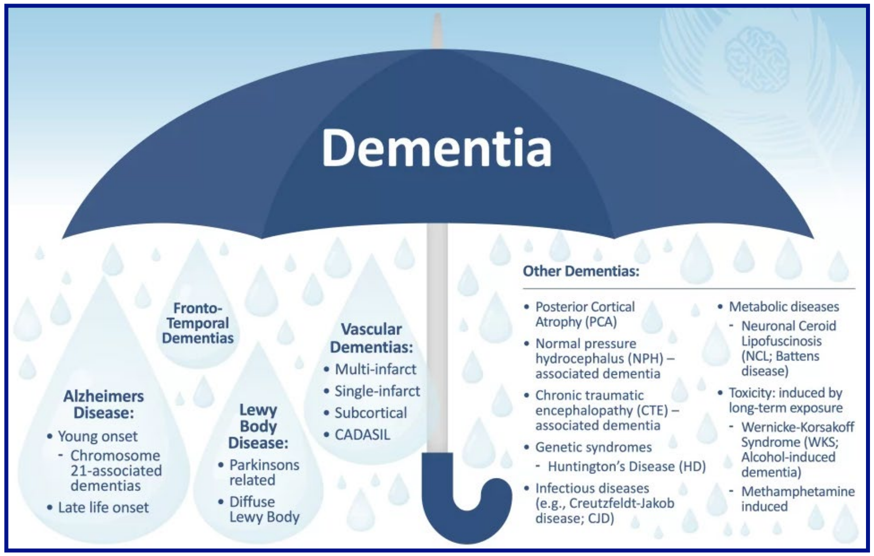
Dementia is not a specific disease, but an overall term describing a wide range of symptoms. It is not normal aging. Dementia is caused by damage to the brain from disease or trauma.

Alzheimer's disease is the most common cause of dementia. Other causes include vascular dementia, Lewy body dementia, frontotemporal dementia, and Parkinson's disease.

## TERMINOLOGY

Throughout this document, a variety of terminology is used:

- Care recipient—this term refers to the person with memory loss or dementia.
- Family caregiver or care partner—these terms refer to the person(s) who is providing most of the support or care for their care recipient.
- Other friends and family—this term refers to people other than the primary care partner who are concerned for their care recipient with dementia and may provide assistance.



# Taking Care of You

# Taking Care of You

**What is my value as a caregiver?**

You have stepped into this role of caregiver willingly or not. Maybe you are retired, and the caregiving role is one you've been expecting to step into, or perhaps you're still working and raising children while you step into this role as a caregiver. No matter how prepared or willing you are, this caregiving responsibility will be both a gift and a cause of frustration. You will be tested, feel immense guilt while caring for the care recipient and when they pass, become exhausted, feel pulled in several directions, and want to isolate yourself. Please know your value as a caregiver to the person you care for is invaluable.

**Why should I take time to build my care map now?**

It is crucial that you do not isolate yourself and recognize that you cannot do this alone, nor should you. Many caregivers will find that friends and family may distance themselves as the caregiving tasks increase. Some friends/family members may feel uncomfortable, some may assume that you shouldn't be bothered, and many others don't know how they can help you during this journey. Building your care map will help you reflect and identify the specific people you have in your support system that you will need to call upon.

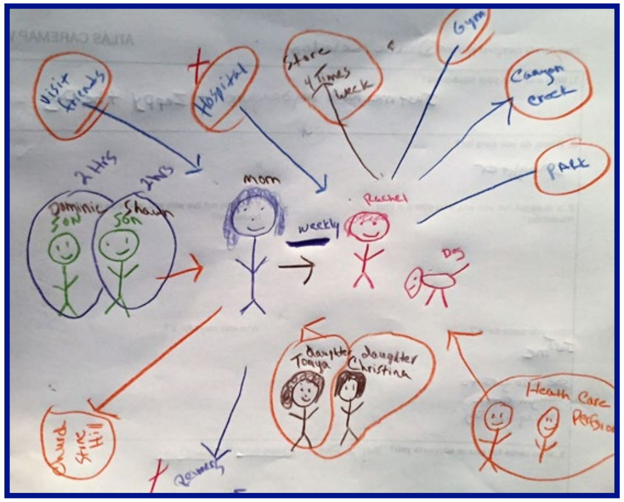
**How do I let others know what I'm experiencing and that I don't want to do it alone?**

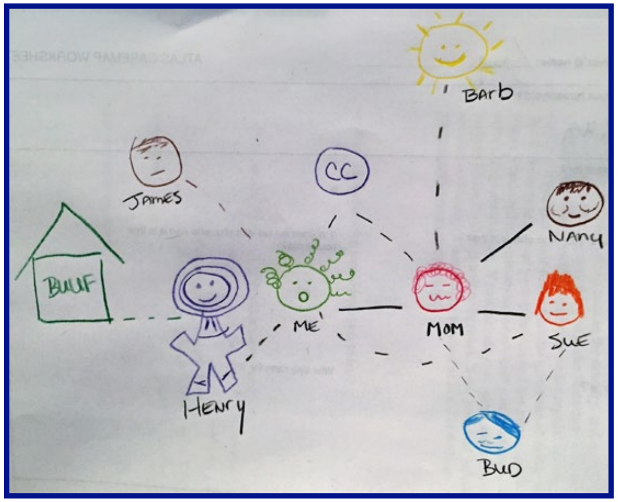
After creating your care map, you will identify at least three of your support team members and determine what they can do to help relieve some of your caregiving tasks. The appendices contain a page titled "You Are Part of My Support Team." It is intended that you tear out this page and share with those support team members you have identified while building your care map.

***Remember that you do not and should not have to do this alone.***

Before you get started on your journey as a caregiver, you need to take a little time to create your personal care map. This is a valuable tool to help you reflect and identify the specific people you have in your support system that you will need to call upon. Use the space provided on the next page to create your personal care map.

As you begin to create your care map, think of pets and people near and far, organizations or professionals that support you, you can connect each with directional lines which can indicate if you provide support to them or they to you, and do not forget to place yourself in the center of the map.





**To build your care map, get your colored pencils out and flip to the next page.**

## Who Are These People? How Can They Help You?

Name:
Relationship to you:
Phone Number:
Email Address:
How can they support you?

- Help research available resources.
- Be an emergency contact.
- Act as a relief caregiver.

Name:
Relationship to you:
Phone Number:
Email Address:
How can they support you?

- Help research available resources.
- Be an emergency contact.
- Act as a relief caregiver.

Name:
Relationship to you:
Phone Number:
Email Address:
How can they support you?

- Help research available resources.
- Be an emergency contact.
- Act as a relief caregiver.

> I had no idea there are so many resources in Idaho. This helps me feel like I'm not alone.
> -Idaho Caregiver

# Wondering & Worried

# Wondering & Worried

## YOU MAY BE WONDERING:

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

## WHAT SHOULD YOU EXPECT IN THIS STAGE?

You notice changes in your care recipient'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.
- Are not taking care of themselves – eating poorly, not bathing, or behaving unsafely.
- Have apathy, increased irritability, anxiety, and depression.

Your care recipient is likely concerned about their memory but may not discuss it. Other friends and family may or may not see or notice any changes.

### YOU MAY:

- Feel irritation with your care recipient’s differing abilities.
- Also feel compassion for your care recipient’s changes, and the confusion and frustration they are experiencing.
- Find that other friends and family don’t notice changes in your care recipient or understand your concerns. They may even downplay your concerns.

### WHAT YOU CAN DO:

- Recognize that any changes may be due to an undiagnosed cognitive decline. Realize that these changes are beyond their control.
- Recognize you are a caregiver. This is a time to seek out information on how best to support yourself while you provide care to your care recipient.
- Learn about normal changes that happen as you age and those that indicate a need to get a check-up.
    - See the *12 Signs and Symptoms of Dementia* on page 56.
    - Review *Forgetfulness: Normal or Not?*[5]
- Keep track of changes you notice. If your care recipient 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. Another way to do this is to attend doctor's appointments and give the provider your Power of Attorney documentation.

- Ask your care recipient 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.
- Earlier diagnosis can open the door for clinical trials or treatments that may only benefit a person in early stages.
- If your care recipient is resistant to a medical check-up, enlist the help of trusted family or friends who may be able to encourage this. Even if your care recipient has not brought up this concern, they are probably still thinking about it. A full medical workup that includes assessment of types and interactions of current medications may help answer questions.
- Call and ask your care recipient's healthcare professional for the Medicare Annual Wellness exam (if they are on Medicare) that includes detection of cognitive impairment along with other screenings. Feel free to share with the professional what you've noticed either in person or in a letter.
- If you don't feel comfortable with your care recipient's current healthcare 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 care recipient has hearing loss, get it checked and addressed—hearing loss makes it harder for a person with memory loss or to communicate. This can lead to misunderstandings and social isolation.
- Make sure both you and your care recipient are making healthy lifestyle choices:
  - Stay active and engaged in social groups, arts, and other activities of interest.
  - Eat vegetables and fruits.
  - Be physically active.
  - Drink in moderation if consuming alcohol.
- 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 care recipient has the ability to do so.**

- Support your care recipient in creating a person-centered plan where they construct and articulate their vision for the future, consider various paths, determine preferred services and supports; helping your person achieve their goals and increase their quality of life as the disease progresses.

## ACTION STEPS

The following steps are important at this point:

☐ Obtain a medical assessment (including a current medication assessment) to find out what may be causing the problems. An early diagnosis provides a head start on getting the information and education needed to provide the best care.

☐ Review the *Decision-Making as We Age*[6] document and watch the *End of Life Planning*[7] Module (available in English and Spanish) created by Idaho Legal Aid Services, Inc.

☐ Complete the following documents. You and your care recipient should have a(n):

- Healthcare Directive–also called a "living will" or "advance directive," regarding treatment preferences.

- Durable Power of Attorney for Healthcare–appointing a healthcare "agent."
- Durable Power of Attorney document–In this document, your care recipient appoints an "agent" to assist with financial and related matters.
- Estate plan–Your care recipient's estate plan may include legal documents, such as a will or a trust, that direct the disposition of their estate upon death.

☐ Review the *Guardianship & Conservatorship Questions & Answers*[8] document by the Idaho State Bar Taxation, Probate & Trust Law Section and have conversations with your care recipient, family, and friends about how this may look in the future.

☐ Have a family meeting to discuss what's happening and necessary next steps.

☐ Register your care recipient in your county's Vulnerable Population Registry, if applicable to the county you live in.

☐ Explore technology that may be helpful to protect and/or assist you and your care recipient, which may include:

- Digital apps.
- Bracelets or watches.
- Communication aids like adapted telephones.
- Home monitoring devices and in-home cameras.

☐ Save the Alzheimer's Association 24/7 Helpline in your phone: 800-272-3900.

> Learning to be patient is hard. Now that I see the disease is the cause of the challenges, I am trying to be more patient.
> -Idaho Caregiver

# Mild Cognitive Impairment

# Mild Cognitive Impairment (MCI)

Mild Cognitive Impairment (MCI) is a slight, yet 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 care recipient with their memory and thinking?
- What can we do to promote our care recipient's well-being?

## WHAT SHOULD YOU EXPECT IN THIS STAGE?

Your care recipient is still independent but may have difficulty paying bills, preparing meals, shopping, and driving. They may forget details, display less ambition, have emotions that go up and down, and be more reliant on you. Be aware that this may be confusing and scary for them. Your care recipient may find success in completing familiar routines and habits.

## YOU MAY:

- Find yourself grieving, feeling angry, depressed, or trying to find ways to control situations.
- Feel irritation with your care recipient's differing abilities that are beyond their control.
- Also feel compassion for your care recipient's changes.

- Find that other friends and family don't notice changes in your care recipient or understand your concerns, and may try to diminish your legitimate concerns. Stay vigilant. An early diagnosis can improve the quality of a care recipient's daily life.

## WHAT YOU CAN DO:

- If not yet evaluated, ask your care recipient's healthcare professional for the Medicare Annual Wellness exam—it includes detection of cognitive impairment along with other screenings.
- Ask your care recipient if you can attend and participate in their medical appointments.
- Inquire about lifestyle changes that may be helpful to slowing of symptoms, overall wellness, and functioning.
- Learn more about MCI.
- Look into what benefits and resources might be available to you through your employer, this will include understanding your leave benefits for down the road.
- Consider keeping a notebook about your care recipient's changes and needs.
- Tell your own healthcare provider that you are caring for a care recipient with cognitive impairment so they can be aware of potential health-related risks you may experience.
- Instead of thinking that your care recipient should just "try harder"—remind yourself that they are doing the best they can.

- Do not do tasks for your care recipient. Allow them to maintain independence and control; be encouraging and patient. Yet, make sure they are able to do these tasks safely.
- Be generous with your patience. Consider paying bills and shopping together so your care recipient can have successes.

### TO HELP YOUR CARE RECIPIENT:

- Support them in managing any heart conditions, high blood pressure, or diabetes, as needed. This may include helping them to manage medications. See tips on this National Institute on Aging webpage: *Managing Medicines for a Person with Alzheimer's*[9] or the *Medicine, Age, and Your Brain PowerPoint Presentation*[10] by the Administration for Community Living (ACL), National Institutes of Health (NIH), and Centers for Disease Control and Prevention (CDC).
- 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: A Guide for Persons with Mild Cognitive Impairment (MCI) & Early Dementia*[11] from the Alzheimer's Association.

## ACTION STEPS

The following steps are important at this point (make sure to review steps on page 18 and complete those):

***Remember! If your care recipient has not yet had a medical assessment, contact their healthcare professional, a geriatrician, a neurologist, and/or a neuropsychologist.***

☐ Discuss with your care recipient the issue of when to discontinue driving and review together the booklet *At the Crossroads: Family Conversations About Alzheimer's Disease, Dementia & Driving*[12] which may be found in the Resource List.

- Complete a *Driving Information and Contract*[13] together. This can be useful when your care recipient no longer remembers the conversation.

☐ Both you and the person you care for should complete healthcare planning documents and file them with the Idaho Department of Health and Welfare, Advance Directives and Registry Services.[14] These include the Healthcare Directive, Physician Orders for Scope of Treatment (POST) form, Durable Power of Attorney for Healthcare. The General Durable Power of Attorney and estate plan should also be completed and filed where necessary.

☐ Work with the person you care for to get listed as an authorized representative at all doctor's offices, with the social security administration, the VA if a veteran, Medicare, and any private insurers.

☐ Start looking at finances to see if applying for Medicaid may be necessary down the road. Remember, Medicaid has minimum federal regulations, the remaining regulations are determined per state. Medicaid coverage in one state may not equate to similar coverage in Idaho. Review these resources that may be helpful for you.

- *Medicare and Medicaid Benefits for People with Dementia: For American Indian and Alaskan Natives.*[15]
- *Medicaid's Role for People with Dementia.*[16]
- *Medicaid Long-term Care Module.*[17]
- *Medicaid for Adults in Idaho.*[18]

☐ Encourage other family and friends to visit regularly.

☐ Look for support groups that serve the caregiver and people with dementia. You will find they provide comfort and sanity.

☐ Encourage your care recipient to get out of the house, maintaining independence while being safe.

☐ Have a family meeting to discuss what's happening, and ways to support the person with memory loss and you as the caregiver, such as: encouraging a check up with a healthcare provider, providing socialization, offering respite so you and your care recipient can have time apart, managing safe medication use, and/or helping with finances or legal planning.

> Knowing the stages of dementia really helps me understand what is happening to my mother and what to expect.
> -Idaho Caregiver

# Early-Stage Dementia

# Early-Stage Dementia

## YOU MAY BE WONDERING:

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

## WHAT SHOULD YOU EXPECT IN THIS STAGE?

Your care recipient has difficulty accomplishing some activities. They may also:

- 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 multitasking.
- 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, guilt, anger, confusion, and frustration.
- Pull away from familiar social circles and isolate.
- Show increasing indifference to normal courtesies of life.
- Have more trouble driving safely.

At the same time, you may find that your care recipient has some kinds of memory that work quite well. They will likely remember stories from long ago and remember how to do things that they are familiar with (like playing an instrument). They may be able to focus more on the present moment, enjoy a sense of humor, and a growing ability to be creative.

**YOU MAY:**

- Feel optimism and/or an early sense of loss and grief.
- Notice a need to provide more reminders and supervision. Become frustrated or have a desire to take over.
- Want to ask for help around the home like housekeeping, errands, laundry, or yard care.
- Be impressed by your care recipient's ability to adapt and grow, during challenges.

### WHAT YOU CAN DO:

- Be an advocate for the right diagnosis and best healthcare. If you're not happy with current care, find a healthcare professional that will work with you and your care recipient together.
- Learn all you can about the disease and tips for communicating supportively with your care recipient. See Communication Tips on page 59.
- Put safety measures in place before they're needed, related to falls, wandering, medication use, harmful cleaning products, guns, power tools, etc. Find information on safety in the Helpful Resources List on page 62.
- Embrace the good days and prepare yourself for the stormy ones.
- Make your life a no guilt zone.
- 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.
- *Complete the Advance Care Planning Information: Being a Healthcare Agent for a Person Living with Dementia*[19] packet which can help guide and answer questions you may have.

- Explore how your care recipient wants to live at the end of their life. Learn about "having the conversation," through the *Your Conversation Starter Guide: For Caregivers of People with Alzheimer's or Other Forms of Dementia*.[20]

### TO HELP YOUR CARE RECIPIENT:

- Provide *Living with Alzheimer's for People with Alzheimer's: Taking Action Workbook*.[21]
- Go along on medical appointments if your care recipient 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. Look for ways to modify your care recipient's favorite activities rather than give them up.
- Encourage them to reach out to friends and get out of the house.
- Reach out to your friends and give your care recipient their space to be alone.
- Promote the best functioning possible. Get hearing 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.
- Encourage them to become an advocate for other people with dementia, reducing the stigma, increasing awareness, and improving policies, services, and supports.
- Consider enrolling in a clinical trial or research study on dementia at a university or memory clinic. Your care recipient 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, and the need to avoid correcting and arguing.
- Consider ways to protect yourself and your care recipient from financial missteps and exploitation, such as removing your care recipient's credit cards (or lower credit limits) and other key wallet documents.

### SERVICES TO CONSIDER:

- Telephonic caregiver supports can be accessed through the AAA,[1] Idaho Community Care Program, or the Idaho Family Caregiver Navigator.[22]
- Educational workshops (can be offered in libraries, churches, senior centers, coffee shops, and other agency spaces throughout Idaho).
- Powerful Tools for Caregivers[23] classes (offered virtual or in-person depending upon where you reside).

- Alzheimer's/dementia seminars (offered virtual or in-person).
- 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[24] and/or the Alzheimer's Reading Room YouTube.[25]
- The Alzheimer's Association MedicAlert with 24/7 Wandering Support[26]—uses a community support network including the police, to locate your care recipient in case they wander. Or, look into locator aids that use active-GPS capability (real-time tracker which can exist within a cell phone or smart watch).

You may be thinking, "I'm tired, afraid, and feel alone with this." You are not alone! Just take one step at a time. Contact one or more of the organizations listed below who offer free caregiver supports:

- 24/7 Helpline: Call 800-272-3900.
- Area Agencies on Aging (AAAs)[1]: Call 208-334-3833 to find your local office.
- Alzheimer's Association Chapters that serve Idahoans.
    - Greater Idaho Chapter[2] call 208-206-0041.
    - Washington State Chapter[3] (**serves North Idaho**) call 800-272-3900.
- Idaho Community Care Program: Call 208-898-9626 or email ccp@a3ssa.com.
- Idaho Family Caregiver Navigator[22] call 208-426-5899.

## ACTION STEPS

The following steps are important at this point (make sure to review steps on pages 18 & 25 and complete those):

☐ Make sure your care recipient either carries an ID or wears MedicAlert+Safe Return or other type of GPS tracking jewelry.

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

☐ Talk to a healthcare professional about the Physician Orders for Scope of Treatment (POST).[27]

☐ Review and complete the *Conversations About Dementia and Living Alone*[28] if your care recipient lives alone.

☐ Have a family meeting to discuss what’s happening and next steps, such as ways the family can support you and the person with memory loss to stay active, healthy, and socially engaged, or help the both of you with decisions and planning around driving or other safety concerns.

- Make a back-up plan to be used if something happens to you. If possible, make not only a plan B but also a plan C–things happen.

☐ Make a list of the daily activities you and the care recipient do and identify which ones you can start enlisting family members to help support. You may not feel you need the help now, but it will empower them and take some of the weight off your shoulders. We need to preserve you and your energy.

☐ Recognize and accept that you will need help. Review your care map at the beginning of this workbook and reach out to your support team.

☐ Consider Care Coordination or Case Management Services: "Guides" for the journey; they can assist with each step. They may be found through the Aging Life Care Association.[4]

☐ Contact the following to inquire about local education and support services mentioned above.

- Area Agency on Aging[1] for your area may be found by clicking on the link or by calling 208-334-3833.
- Alzheimer's Association Chapters that serve Idahoans.
    - Greater Idaho Chapter[2] call 208-206-0041.
    - Washington State Chapter[3] (**serves North Idaho**) call 800-272-3900.

- Idaho Community Care Program: Call 208-898-9626 or email ccp@a3ssa.com.
- Idaho Family Caregiver Navigator[22] can support caregivers at 208-426-5899.
- If your care recipient belongs to the disability community or the LGBTQ community, it is important to know that although the agencies listed above should be able to help, you might also want to connect with specialized resources.
    - The Idaho Center for Independent Living that serves your area can be found here silc.idaho.gov/idaho-centers-for-independent-living.
    - Sage is a national organization that advocates and provides information for LGBTQ elders and can be found here www.sageusa.org.

# Mid-Stage Dementia

> I shouldn't have jumped in to do everything for my husband right away, I could have preserved some of my energy and frustration...it could have also helped him feel competent for longer.
>
> -Idaho Caregiver

# Mid-Stage Dementia

## YOU MAY BE WONDERING:

- What can I do to make the home safer?
- What do we do if our care recipient 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 care recipient's life more enjoyable?

## WHAT SHOULD YOU EXPECT IN THIS STAGE?

In the middle stage, confusion becomes more obvious. Your care recipient will have increasing needs for care and supervision. They may:

- Have more trouble with memory, such as recalling their own address or personal history.
- Miss or overtake daily medications.
- 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.
- Experience overwhelming sadness and may not be able to explain why.

- Experience speech problems, limiting their ability to communicate the emotions they are feeling.
- End up confused due to not being able to timely communicate they are sick, in pain, or need medical attention. Make sure the healthcare provider checks them for delirium and doesn't dismiss your care recipient's actions as normal behaviors of dementia. You, as the caregiver, may not feel they have this, but you know your care recipient best.
- Resist bathing or other personal care. May have episodes of incontinence.
- Have abilities that vary from one day to the next, such as awareness of what day it is or how to read a clock.
- 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.

- Have delusions (false beliefs) or hallucinations (seeing/hearing things that aren’t there). Do not argue with them. This is their reality. Support them to defuse the situation as safely as possible.
- 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 your moods 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 can 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. Or they may be pulling away with the false understanding that you have it all under control, and you don’t need their help.
- Have the opportunity to get to know your local police better due to your care recipient calling them due to delusions or hallucinations, or you are calling the police because your care recipient is missing, or you feel unsafe.

## 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 care recipient.
- Try not to mistake your care recipient's moodiness for rudeness.
- Practice not taking behaviors personally—**it's the disease**.
- Make it a point to laugh.
- Ask for help with taking care of the home or providing care: housekeeping, errands, yard care, handy person, or in-home assistance for your care recipient.
- 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. Remember, your care recipient may be more sensitive to your moods and behaviors, so this outlet is necessary for you both.

- Take safety precautions related to falls, wandering, medication use, harmful cleaning products, guns, power tools, etc.
- If your care recipient is still driving, enlist the help of their healthcare provider to get them to stop. Call the Alzheimer's Association 24/7 toll-free Helpline: 800-272-3900 for additional ideas.
- Look into support and service options to help maintain current living arrangements, 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 CARE RECIPIENT:

- Encourage family and close friends to learn communication tips and techniques and to help provide activities your care recipient still enjoys. The Communication and Alzheimer's website from the Alzheimer's Association[29] is a great start.
    - Refer them to the Alzheimer's Association website or 24/7 toll-free Helpline: 800-272-3900.
- Try to provide kindness, understanding, and acceptance to them and yourself.
- Channel their energy—go for regular walks together, encourage them to help with chores like vacuuming, sweeping, folding laundry, and gardening. It may not be perfect, but it keeps them active and busy.

- Simplify tasks and activities, break activities into smaller steps. Allow more time for your care recipient to accomplish them. Consider a "fidget blanket."
- Reminisce—look at old photo albums, a memory book, or old videos.
- Make sure your care recipient gets ongoing medical care.
- If you notice any SUDDEN changes in behavior, call your care recipient's physician. This can be a sign of an infection or other medical issue.
- Talk to their doctor about completing a Physician Orders for Scope of Treatment (POST) form[27] and ask for a referral to a physical or occupational therapist for an in-home safety evaluation.
- Go to the Alzheimer's Association's online Caregiver Center[30] to find helpful tips on daily care such as activities, providing personal care, and managing incontinence.

### 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.

***Use therapeutic fibbing and diversion to help comfort, alleviate stress, and meet individuals in 'their' reality.***

- Consider adult day services. They can offer your care recipient activity, exercise, and socialization and provide you with some time for yourself.
- Local library resources and classes.
- In-home care to assist with bathing, dressing, getting ready in the morning or evening, and other personal care tasks/routines.
- Counseling to get emotional support and to handle your own grief, depression, and anger.
- If you haven't investigated or used yet:
    - Powerful Tools for Caregivers.[23]
    - Support Group.
    - Respite Care (in or out of the home).
    - Consultants who specialize in caregiving issues and can assist with behaviors.
    - MedicAlert with 24/7 Wandering Support[26] or GPS locator program.
    - Behavior education and consultation, such as Savvy Caregiver (savvycaregiver.com), a training program to increase dementia skills, or STAR-C, a deescalation training program.

- Contact the following to inquire about local education and support services mentioned above.
  - Area Agency on Aging[1] for your area may be found by clicking on the link or by calling 208-334-3833.
  - Alzheimer's Association Chapters that serve Idahoans.
    - Greater Idaho Chapter[2] call 208-206-0041.
    - Washington State Chapter[3] (**serves North Idaho**) call 800-272-3900.
  - Idaho Community Care Program: Call 208-898-9626 or email ccp@a3ssa.com.
  - Idaho Family Caregiver Navigator[22] can support caregivers at 208-426-5899.
- If your care recipient belongs to the disability community or the LGBTQ community, it is important to know that although the agencies listed above should be able to help, you might also want to connect with specialized resources.
  - The Idaho Center for Independent Living that serves your area can be found here silc.idaho.gov/idaho-centers-for-independent-living.
  - Sage is a national organization that advocates and provides information for LGBTQ elders and can be found here www.sageusa.org.

## ACTION STEPS

See Action Steps on pages 18, 25, & 34 and do the following:

☐ Register your care recipient in your county's Vulnerable Population Registry, if applicable to the county you live in.

☐ 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.
- Care recipient's wishes.
- Required tasks and who will take on what (social activities, medical appointments, care coordination, personal care, etc.).
- Who is taking over caregiving tasks to relieve the caregiver for a few hours or days (during the early stages taking the care recipient somewhere else is also helpful).
- How else to support the care recipient and you.

- What financial steps need to be taken to prepare for the increasing level of care, determine if that level of care be provided at home safely, and if it is time to look into Medicaid.
- Necessary next steps.

☐ If help with financing care is needed, contact your local Area Agency on Aging office.

☐ Revisit end-of-life planning conversation, discuss and document how your care recipient wants to live at the end of their life, including medical care wanted or not wanted, comfort measures, and palliative and hospice care.

☐ Did you know that palliative care is not end of life care? It is available to people who have illnesses and aims to optimize quality of life for the person. Talk with your care recipient’s healthcare provider about when the best time may be to bring palliative care into the care plan.

### WANT TO LEARN MORE ABOUT RESIDENTIAL CARE OPTIONS?

In addition to services that can help a person with dementia to stay at home, there are many different types of homes or facilities that provide long-term care. Residential care options in Idaho include adult family homes, assisted living facilities, nursing homes, and Certified Family Homes.

- Find out more and what’s available in your area by visiting the Medicaid Assistance Care and Facilities website from the Idaho Department of Health and Welfare.[31]

### ARE YOU FEELING YOU NEED ASSISTANCE AND CAN'T DO THIS ANYMORE?

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

- Area Agency on Aging[1] for your area may be found by clicking on the link or by calling 208-334-3833.
- Alzheimer's Association Chapters that serve Idahoans.
    - Greater Idaho Chapter[2] call 208-206-0041.
    - Washington State Chapter[3] (**serves North Idaho**) call 800-272-3900.
- Idaho Community Care Program: Call 208-898-9626 or email ccp@a3ssa.com.
- Idaho Family Caregiver Navigator[22] can support caregivers at 208-426-5899.
- If your care recipient belongs to the disability community or the LGBTQ community, it is important to know that although the agencies listed above should be able to help, you might also want to connect with specialized resources.
    - The Idaho Center for Independent Living that serves your area can be found here silc.idaho.gov/idaho-centers-for-independent-living.
    - Sage is a national organization that advocates and provides information for LGBTQ elders and can be found here www.sageusa.org.

# Late-Stage Dementia

> There are good days! Remember to focus on the good days.
> -Idaho Caregiver

# Late-Stage Dementia

## YOU MAY BE WONDERING:

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

## WHAT SHOULD YOU EXPECT IN THIS STAGE?

In the late stage, your care recipient is completely dependent for personal care activities. They may:

- Require more assistance to keep them safe such that is generally offered in a long-term care facility.
- Not recognize you or others by name. This does not mean they don’t know (or feel) who you are.
- Have increasing difficulty communicating. They 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 and urinary tract infections.

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 care recipient is near.
- Experience guilt in feeling you wish your care recipient would die.
- Find that friends and family are also experiencing grief.

### WHAT YOU CAN DO:

- Be gentle with yourself and your care recipient. Respect yourself for the love and support you have provided for your care recipient 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 care recipient's healthcare 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 CARE RECIPIENT:

- Maintain simple routines with a mix of rest and activity. Get outdoors for fresh air. Go for walks and 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 care recipient enjoys. Sing!
- Appeal to the senses—squeeze fresh orange juice, smell the roses, and use scented lotions.
- Encourage other family and friends to visit on a regular basis to provide kind words, share memories, loving hugs, and comfort.

### SERVICES TO CONSIDER:

- Respite.
- In-home or residential care.
- Palliative care.
- Hospice care.

- Support group.
- Counseling or other emotional support for yourself.

### ACTION STEPS:

See Action Steps on pages 18, 25, 34, & 46 and do the following:

☐ Discuss with the healthcare provider when palliative care should be brought in and seek it out.

☐ Discuss with the healthcare provider when hospice care should be brought in and seek out options.

☐ Have a family meeting to discuss:
- What's happening.
- Care recipient's wishes.
- Required tasks and who will take on what (social activities, medical appointments, care coordination, personal care, etc.).
- Who is taking over caregiving tasks to relieve the caregiver for a few hours or days.
- If the care recipient is still able to receive safe care at home or if it is time to look at a care facility.

- How else to support the care recipient and you.
- Necessary next steps.

### ARE YOU FEELING WORN OUT FROM CARING AND GRIEVING?

Reach out to others in a similar situation, a care coordinator, a counselor, the Alzheimer's Association, or your local Area Agency on Aging for support.

- Area Agency on Aging[1] for your area may be found by clicking on the link or by calling 208-334-3833.
- Alzheimer's Association Chapters that serve Idahoans.
    - Greater Idaho Chapter[2] call 208-206-0041.
    - Washington State Chapter[3] (**serves North Idaho**) call 800-272-3900.
- Idaho Community Care Program: Call 208-898-9626 or email ccp@a3ssa.com.
- Idaho Family Caregiver Navigator[22] can support caregivers at 208-426-5899.
- If your care recipient belongs to the disability community or the LGBTQ community, it is important to know that although the agencies listed above should be able to help, you might also want to connect with specialized resources.
    - The Idaho Center for Independent Living that serves your area can be found here silc.idaho.gov/idaho-centers-for-independent-living.
    - Sage is a national organization that advocates and provides information for LGBTQ elders and can be found here www.sageusa.org.

# Dementia “Tip Sheets”

# Dementia "Tip Sheets"

## 12 SIGNS AND SYMPTOMS OF DEMENTIA

- Experiencing memory loss, poor judgment, and confusion.
- Difficulty speaking, understanding and expressing thoughts, or reading and writing.
- Wandering and getting lost in a familiar neighborhood.
- Trouble handling money responsibly and paying bills.
- Repeating questions.
- Using unusual words to refer to familiar objects.
- Taking longer to complete normal daily tasks.
- Losing interest in normal daily activities or events.
- Hallucinating or experiencing delusions or paranoia.
- Acting impulsively.
- Not caring about other people's feelings.
- Losing balance and problems with movement.

**See page 78 for the You Are Part of My Support Team Tear Out Sheet.**

For more information on "Related Dementias", go to: [www.nia.nih.gov/health/what-is-dementia#signs](www.nia.nih.gov/health/what-is-dementia#signs).

## STAGES OF ALZHEIMER'S DISEASE & DEMENTIA

(Other types of dementias may differ or align with below)

### Early-Stage Alzheimer's Disease

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

### Mid-Stage Alzheimer's Disease

- Increasing needs for care and supervision.
- More trouble with memory, such as 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.
- May resist bathing or other personal care.
- May experience overwhelming sadness and may not be able to explain why.
- Abilities that vary from one day to the next.
- Have episodes of incontinence.
- May complain of neglect or blame 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, and 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 Alzheimer’s Disease**

- 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. They may use “word salad” (mixed up words) or be speechless. Nonverbal communication may work best.

- Frequently or totally incontinent.
- Rigidity, immobility, jerks, or seizures.
- May feel deep emotions and may scream, moan, or flail.
- Vulnerable to infections, especially pneumonia.

## COMMUNICATION TIPS

Brain changes make it difficult for a person with dementia to say what they want and understand what others are saying. Your care recipient may have trouble coming up with the right words, 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 care recipient's words may at times make little or no sense to you. They 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 care recipient know you're listening and trying to understand. Keep your voice gentle. Hold the person's hand while you talk. Smile, nod, and make appropriate eye contact.
- Show respect. Offer your care recipient undivided attention, don't multi-task. Include your care recipient 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.

**If at any time you feel that you are overwhelmed, please reach out to friends, family, faith community, the 24/7 Helpline through the Alzheimer’s Association, or the 988 Crisis Line for help and support. You do not have to do this alone.**

- 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 care recipient 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 nonverbal 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 care recipient, 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.
- Accept that their reality may not be yours. Using therapeutic fibbing and diversion can help comfort, alleviate stress, and meet individuals in 'their reality.' An example may be, if your care recipient asks for their mom, do not remind them that she is dead; this will only cause your person to go through a grieving period and put focus onto their memory deficit.

It's important to remember that your care recipient 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. The Alzheimer's Association or your local Area Agency on Aging office will know of such opportunities. Reach out today!

***The Communication and Alzheimer's website from the Alzheimer's Association is a great resource to turn to.***[29]

## HELPFUL RESOURCES

If links are broken, organizations and resources should be easy to find by searching the resource or organization name online.

**Organizational Websites**

- 24/7 Helpline – Alzheimer's Association: Call 800-272-3900 or visit www.alz.org.
- Acute and Continuing Care: Hospice Agencies – Idaho Department of Health and Welfare: www.healthandwelfare.idaho.gov/providers/acute-and-continuing-care/hospice-agencies.
- Administration for Community Living (information on brain health basics, medications, brain injuries, and dementia): https://acl.gov/.
- Aging Life Care Association (provide private geriatric care management services): www.aginglifecare.org.
- Aging Strong Programs by Jannus (Powerful Tools for Caregivers, Legacy Corps Caregiver Supports, Foster Grandparent Program, etc.): www.agingstrong.org.

- Alzheimers.gov (information on clinical trials, Alzheimer's, dementias, caregiver resources, professional information, etc.): www.alzheimers.gov.
- Alzheimer's Association Chapters that serve Idahoans.
  - Greater Idaho Chapter: www.alz.org/idaho or call 208-206-0041.
  - Washington State Chapter (**serves North Idaho**): www.alz.org/alzwa or call 800-272-3900.
- Alzheimer's Disease and Healthy Aging – Centers for Disease Control and Prevention: https://www.cdc.gov/aging/index.html.
- Alzheimer's Reading Room YouTube Videos: www.youtube.com/c/Alzheimersreadingroom1?app=desktop.
- Area Agency on Aging (find your local agency): https://aging.idaho.gov/area-agencies-on-aging/ or call 208-334-3833.
- Caregiver Center – Alzheimer's Association: www.alz.org/help-support/caregiving.
- Idaho Commission on Aging (information for seniors, people with disabilities, and caregivers): https://aging.idaho.gov/.
- Medicaid for Elderly or Adults with Disabilities – Idaho Department of Health and Welfare: https://healthandwelfare.idaho.gov/services-programs/medicaid-health/about-medicaid-elderly-or-adults-disabilities.
- Medicaid Assisted Care and Facilities – Idaho Department of Health and Welfare: https://healthandwelfare.idaho.gov/services-programs/medicaid-health/assisted-care-and-facilities.

- Eldercare Locator – Administration for Community Living (a public service connecting you to services for older adults and their families): https://eldercare.acl.gov/Public/Index.aspx or call 1-800-677-1116.
- Idaho Family Caregiver Navigator: www.caregivernavigator.org or call 208-426-5899.
- Brain Health – International Association for Indigenous Aging: https://iasquared.org/brain-health/.
- National Task Group on Intellectual Disabilities and Dementia Practices: www.the-ntg.org.
- Sage Advocacy & Services for LGBTQ+ Elders: www.sageusa.org or call 877-360-5428.
- Senior Health Insurance Benefits Advisors – Idaho Department of Insurance: https://doi.idaho.gov/shiba/.
- U.S. Department of Veterans Affairs: www.va.gov, call the Veteran Crisis Line 988, and then select 1, or text 838255.
- African Americans Against Alzheimer's – UsAgainstAlzheimer's: www.usagainstalzheimers.org/networks/african-americans.
- Latinos Against Alzheimer's – UsAgainstAlzheimer's: www.usagainstalzheimers.org/networks/latinos.
- Women's Alzheimer's Movement – Cleveland Clinic: https://thewomensalzheimersmovement.org/.

**Information and Documents**

- Alzheimer’s Caregiving – National Institute on Aging: www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide.
- *At the Crossroads: Family Conversations About Alzheimer’s, Dementia, and Driving* – The Hartford Center for Mature Market Excellence: http://s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf.
- Communication and Alzheimer’s – Alzheimer’s Association: https://www.alz.org/help-support/caregiving/daily-care/communications.
- *Conversations About Dementia and Living Alone* – Alzheimer Society of Canada: http://alzheimer.ca/peel/sites/peel/files/documents/conversations-about-dementia-and-living-alone.pdf.
- *Decision-Making As We Age* – Idaho Legal Aid Services, Inc.: http://www.idaholegalaid.org/sites/idaholegalaid.org/files/Decision%20Making%20As%20We%20Age%20Brochure.pdf.
- Dementia and Driving – Alzheimer’s Association: www.alz.org/care/alzheimers-dementia-and-driving.asp.
- Dementia Care (Including Alzheimer’s Disease) – U.S. Department of Veterans Affairs: www.va.gov/GERIATRICS/pages/Alzheimers_and_Dementia_Care.asp.
- *Driving Information and Contract* – Alzheimer’s Association: www.alz.org/media/documents/alzheimers-dementia-driving-info-contract-ts.pdf.

- *Forgetfulness: Normal or Not?* – National Institute on Aging: www.nia.nih.gov/sites/default/files/forgetfulness-infographic-508.pdf.
- Home Safety and Alzheimer’s Disease – National Institute on Aging: www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease/introduction.
- Idaho Community Care Program (provides support to individuals caring for a person with memory loss or dementia): Call 208-898-9626 or email ccp@a3ssa.com.
- *Living Well: A Guide for Persons with Mild Cognitive Impairment (MCI) & Early Dementia* – Alzheimer’s Association: www.actonalz.org/pdf/Living-Well.pdf.
- *Living with Alzheimer’s for People with Alzheimer’s: Taking Action Workbook* – Alzheimer’s Association: www.actonalz.org/pdf/Taking-Action.pdf.
- Managing Medicines for a Person With Alzheimer’s – National Institute on Aging: www.nia.nih.gov/health/managing-medicines-person-alzheimers.
- MedicAlert with 24/7 Wandering Support – Alzheimer’s Association: https://www.alz.org/dsw/helping_you/medicalert_safe_return.
- *Medicare and Medicaid for Persons with Dementia: For American Indians and Alaskan Natives* – Healthcare.gov: https://www.cms.gov/outreach-and-education/american-indian-alaska-native/aian/downloads/medicare-and-medicaid-benefits-for-people-with-dementia.pdf.
- Your Rights & Resources: LGBTQ+ and Dementia – Sage Advocacy & Services for LGBTQ+ Elders: www.sageusa.org/resource-posts/issues-brief-lgbt-and-dementia.

### Resources for Legal and Advance Planning

- *Advance Care Planning Information: Being a Healthcare Agent for a Person Living with Dementia* – Idaho Healthcare Directive Registry: https://publicdocuments.dhw.idaho.gov/WebLink/DocView.aspx?id=22310&dbid=0&repo=PUBLIC-DOCUMENTS.
- Advance Directives and Registry Services – Idaho Department of Health and Welfare: https://healthandwelfare.idaho.gov/services-programs/birth-marriage-death-records/advance-directives-and-registry-services.
- *End of Life Planning Module (English and Spanish (Español))* – Idaho Legal Aid Services, Inc.: https://www.idaholegalaid.org/node/2777/end-life-planning-module-english-and-spanish-espanol.
- Find a Lawyer – National Academy of Elder Law Attorneys: www.naela.org/findlawyer.
- *Guardianship & Conservatorship Questions and Answers* – Idaho State Bar Taxation, Probate & Trust Law Section: https://isb.idaho.gov/wp-content/uploads/bro_guardianship.pdf.
- Legal Assistance: Assistance Preparing for or Resolving Legal Issues – Idaho Commission on Aging: https://aging.idaho.gov/stay-safe/legal-assistance/.
- Healthcare Advance Directive Documents (includes Physician Orders for Scope of Treatment (POST), Durable Power of Attorney, Living Will, and Advance Directive & Emergency Contact Notification Card) – Idaho Advance Directives and Registry Services: https://healthandwelfare.idaho.gov/services-programs/birth-marriage-death-records/advance-directives-and-registry-services.

- Powers of Attorney and Advanced Directives Self-Help Forms – Idaho Legal Aid:
  - Living Will and Durable Power of Attorney for Health Care: https://www.idaholegalaid.org/node/2233/living-will-and-durable-power-attorney-health-care.
  - Durable Power of Attorney for Financial Affairs: https://www.idaholegalaid.org/node/2234/durable-power-attorney-financial-affairs.
  - Power of Attorney Revocation Form: https://www.idaholegalaid.org/node/2454/power-attorney-revocation-form.
- Questions and Answers About Wills – Idaho Legal Aid: www.idaholegalaid.org/node/1271/questions-and-answers-about-wills.
- *Your Conversation Starter Guide: For Caregivers of People with Alzheimer's or Other Forms of Dementia* – The Conversation Project, Institute for Healthcare Improvement. https://theconversationproject.org/wp-content/uploads/2020/12/DementiaGuide.pdf.

**Resources on Other Dementia**

- Alzheimer's and Dementia – National Institute on Aging: https://www.nia.nih.gov/health/alzheimers-and-dementia.
- Alzheimer's Disease and Related Dementias – Idaho Department of Health and Welfare: https://healthandwelfare.idaho.gov/health-wellness/diseases-conditions/alzheimers-disease-and-related-dementias.

- The Association for Frontotemporal Degeneration: https://www.theaftd.org/.
- Frontotemporal Dementia and Other Frontotemporal Disorders – National Institute of Neurological Disorders and Stroke: https://www.ninds.nih.gov/health-information/disorders/frontotemporal-dementia-and-other-frontotemporal-disorders.
- Lewy Body Dementia Association: www.lbda.org or call 800-539-9767.
- Lewy Body Dementia: Information for Patients, Families and Caregivers – National Institute of Neurological Disorders and Stroke: https://catalog.ninds.nih.gov/publications/lewy-body-dementia-information-patients-families-and-professionals.

**Action Steps Summary**

- Obtain a medical assessment of memory loss/cognitive impairment and diagnosis for your care recipient – this opens the door to necessary planning. This process should start with your healthcare provider and may involve other specialists, such as a geriatrician, a neurologist, and/or a neuropsychologist.
- Encourage your care recipient to get out of the house, maintaining independence while being safe.
- Review the *Decision-Making as We Age*[6] document and watch the *End of Life Planning*[7] Module (available in English and Spanish) created by Idaho Legal Aid Services, Inc.
- Discuss and document how your care recipient wants to live at the end of their life, including medical care wanted or not wanted, comfort measures, and palliative and hospice care.

- Complete the following documents. You and your care recipient should have a(n):
    - Healthcare Directive–also called a "living will" or "advance directive," regarding treatment preferences.
    - Durable Power of Attorney for Healthcare–appointing a healthcare "agent."
    - Durable Power of Attorney document–In this document, your care recipient appoints an "agent" to assist with financial and related matters.
    - Estate plan–Your care recipient's estate plan may include legal documents, such as a will or a trust, that direct the disposition of their estate upon death.
- Talk to a healthcare professional about the Physician Orders for Scope of Treatment (POST).[27]
- Review the *Guardianship & Conservatorship Questions & Answers*[8] document by the Idaho State Bar Taxation, Probate & Trust Law Section and have conversations with your care recipient, family, and friends about how this may look in the future.
- Have a family meeting to discuss:
    - What's happening.
    - Care recipient's wishes.
    - Required tasks and who will take on what (social activities, medical appointments, care coordination, personal care, etc.).
    - Who is taking over caregiving tasks to relieve the caregiver for a few hours or days (during the early stages taking the care recipient somewhere else is also helpful).

    - What financial steps need to be taken to prepare for the increasing level of care, determine if that level of care can be provided at home safely, and if it is time to look into Medicaid.
    - How else to support the care recipient and you, and necessary next steps.
- Review and complete the *Conversations About Dementia and Living Alone*[28] if your care recipient lives alone.
- Register your care recipient in your county’s Vulnerable Population Registry, if applicable to the county you live in.
- Explore technology that may be helpful to protect and/or assist you and your care recipient, which may include:
    - Digital apps.
    - Bracelets or watches.
    - Communication aids like adapted telephones.
    - Home monitoring devices and in-home cameras.
- Save the Alzheimer’s Association 24/7 Helpline in your phone: 800-272-3900.
- If help with financing care is needed, contact your local Area Agency on Aging office.
- Make a back-up plan to be used if something happens to you. If possible, make not only a plan B but also a plan C–things happen.
- If your care recipient is still driving, review together the booklet *At the Crossroads:*

*Family Conversations about Alzheimer's, Dementia, and Driving*[12] which may be found in the Resource.

- Complete a *Driving Information and Contract*[13] together. This can be useful when your care recipient no longer remembers the conversation.
- Make sure your care recipient either carries an ID or wears MedicAlert with 24/7 Wandering Support[26] or other type of GPS tracking jewelry.
- Contact the following to inquire about local education and support services.
  - Area Agency on Aging[1] for your area may be found by clicking on the link or by calling 208-334-3833 to find your local office and more information.
  - Alzheimer's Association Chapters that serve Idahoans.
    - Greater Idaho Chapter[2] call 208-206-0041.
    - Washington State Chapter[3] (**serves North Idaho**) call 800-272-3900.
  - Idaho Community Care Program: Call 208-898-9626 or email ccp@a3ssa.com.
  - Idaho Family Caregiver Navigator[22] can support caregivers at 208-426-5899.
- Consider Care Coordination or Case Management Services: "Guides" for the journey; they can assist with each step. They may be found through the Aging Life Care Association.[4]

- Discuss with the healthcare provider when palliative care should be brought in and seek it out.
- Discuss with the healthcare provider when hospice care should be brought in and seek out options.

## Website References

1. Area Agencies on Aging (AAAs): aging.idaho.gov/area-agencies-on-aging.
2. Alzheimer's Association, Greater Idaho Chapter: www.alz.org/idaho.
3. Alzheimer's Association, Washington State Chapter (**Serves North Idaho**): www.alz.org/alzwa.
4. Aging Life Care Association: www.aginglifecare.org.
5. *Forgetfulness: Normal or Not?* – National Institute on Aging: www.nia.nih.gov/sites/default/files/forgetfulness-infographic-508.pdf.
6. *Decision-Making As We Age* – Idaho Legal Aid Services, Inc.: http://www.idaholegalaid.org/sites/idaholegalaid.org/files/Decision%20Making%20As%20We%20Age%20Brochure.pdf.
7. *End of Life Planning Module (English and Spanish (Español))* – Idaho Legal Aid Services, Inc.: https://www.idaholegalaid.org/node/2777/end-life-planning-module-english-and-spanish-espanol.

8. *Guardianship & Conservatorship Questions and Answers* – Idaho State Bar Taxation, Probate & Trust Law Section: https://isb.idaho.gov/wp-content/uploads/bro_guardianship.pdf.

9. Managing Medicines for a Person With Alzheimer’s – National Institute on Aging: www.nia.nih.gov/health/managing-medicines-person-alzheimers.

10. *Medicine, Age, and Your Brain PowerPoint Presentation* – Administration for Community Living, National Institutes of Health, and Centers for Disease Control and Prevention: https://acl.gov/brain-health.

11. *Living Well: A Guide for Persons with Mild Cognitive Impairment (MCI) & Early Dementia* – Alzheimer’s Association: www.actonalz.org/pdf/Living-Well.pdf.

12. *At the Crossroads: Family Conversations About Alzheimer’s, Dementia, and Driving* – The Hartford Center for Mature Market Excellence: http://s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf.

13. *Driving Information and Contract* – Alzheimer’s Association: www.alz.org/media/documents/alzheimers-dementia-driving-info-contract-ts.pdf.

14. Advance Directives and Registry Services – Idaho Department of Health and Welfare: https://healthandwelfare.idaho.gov/services-programs/birth-marriage-death-records/advance-directives-and-registry-services.

15. *Medicare and Medicaid for Persons with Dementia: For American Indians and Alaskan Natives* – Healthcare.gov: https://www.cms.gov/outreach-and-education/american-indian-alaska-native/aian/downloads/medicare-and-medicaid-benefits-for-people-with-dementia.pdf.

16. *Medicaid's Role for People with Dementia* – The Kaiser Commission on Medicaid and the Uninsured: www.kff.org/medicaid/issue-brief/medicaids-role-for-people-with-dementia.

17. Medicaid Long-term Care Module – Idaho Legal Aid Services, Inc.: https://www.idaholegalaid.org/node/2778/medicaid-long-term-care-module-english-and-spanish-espanol.

18. Medicaid for Adults – Idaho Department of Health and Welfare: https://healthandwelfare.idaho.gov/services-programs/medicaid-health/about-medicaid-adults.

19. *Advance Care Planning Information: Being a Healthcare Agent for a Person Living with Dementia* – Idaho Healthcare Directive Registry: https://publicdocuments.dhw.idaho.gov/WebLink/DocView.aspx?id=22310&dbid=0&repo=PUBLIC-DOCUMENTS.

20. *Your Conversation Starter Guide: For Caregivers of People with Alzheimer's or Other Forms of Dementia* – The Conversation Project, Institute for Healthcare Improvement. https://theconversationproject.org/wp-content/uploads/2020/12/DementiaGuide.pdf.

21. *Living with Alzheimer's for People with Alzheimer's: Taking Action Workbook* – Alzheimer's Association: www.actonalz.org/pdf/Taking-Action.pdf.

22. Idaho Family Caregiver Navigator: www.caregivernavigator.org.

23. Powerful Tools for Caregivers: www.agingstrong.org/powerful-tools-for-caregivers.

24. Alzheimer's Association: www.alz.org.
25. Alzheimer's Reading Room YouTube Videos: www.youtube.com/c/Alzheimersreadingroom1?app=desktop.
26. MedicAlert with 24/7 Wandering Support – Alzheimer's Association: https://www.alz.org/dsw/helping_you/medicalert_safe_return.
27. Physician Orders for Scope of Treatment (POST), Advance Directives and Registry Services – Idaho Department of Health and Welfare: https://healthandwelfare.idaho.gov/advancedirective.
28. *Conversations About Dementia and Living Alone* – Alzheimer Society of Canada: http://alzheimer.ca/peel/sites/peel/files/documents/conversations-about-dementia-and-living-alone.pdf.
29. Communication and Alzheimer's – Alzheimer's Association: https://www.alz.org/help-support/caregiving/daily-care/communications.
30. Caregiver Center – Alzheimer's Association: www.alz.org/help-support/caregiving.
31. Medicaid Assisted Care and Facilities – Idaho Department of Health and Welfare: https://healthandwelfare.idaho.gov/services-programs/medicaid-health/assisted-care-and-facilities.

**Created in Partnership with the Idaho Alzheimer's Disease and Related Dementias (ADRD) Alliance.**

The Idaho ADRD Alliance was launched in November of 2021 and serves as a collective voice to address ADRD issues in Idaho. All voices are needed to better understand ADRD in Idaho, and all are invited to participate in and provide input to the alliance. The work of the ADRD Alliance aligns with and supports the ADRD Program commitment to the Idaho Legislature and the Centers for Disease Control and Prevention's goals, ensuring that a wide array of considerations are incorporated into the program's direction and work. The ADRD Alliance holds quarterly meetings virtually, allowing for statewide participation. The ADRD Alliance is comprised of ADRD partners, stakeholders, and a steering committee.

The ADRD Alliance does not serve as a governing body to a public agency and is not empowered with making policy decisions. The alliance is managed by the Idaho Alzheimer's Disease and Related Dementias Program in the Division of Public Health, Idaho Department of Health and Welfare.

To request this publication in another language, please email: adrd@dhw.idaho.gov.

To learn more or get involved:

- Idaho Alzheimer's Disease and Related Dementias Alliance: healthandwelfare.idaho.gov/health-wellness/diseases-conditions/alzheimers-disease-and-related-dementias.

**Adapted from the Washington State Dementia Action Collaborative's Dementia Road Map: A Guide for Family and Care Partners.**

Dementia Action Collaborative
Washington State

# You Are Part of My Support Team

(Tear out this page and share)

**Introduction:**

**You are part of my support team:**

**I would like you to support me by:**

**Introduction:**

**You are part of my support team:**

**I would like you to support me by:**

**Introduction:**

**You are part of my support team:**

**I would like you to support me by:**

**Introduction:**

**You are part of my support team:**

**I would like you to support me by:**

**Introduction:**

**You are part of my support team:**

**I would like you to support me by:**

IDAHO DEPARTMENT OF
HEALTH & WELFARE
ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

May 2024