Dementia Action Collaborative
Washington State

Dementia Road Map:
A Guide for Family and Care Partners

Dementia Road Map: **A Guide for Family and Care Partners**

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DEMENTIA ROAD MAP OVERVIEW

Wondering & Worried

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

Mild Cognitive Impairment (MCI)

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

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Early-Stage Dementia

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

Mid-Stage Dementia

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

Late-Stage Dementia

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

Washington State Dementia Road Map for 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 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.

Worried about memory loss in a loved one?

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

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

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

Guides for the journey

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

- Area Agencies on Aging (AAAs) are trusted sources of information and assistance, where older adults can turn to find specialized information, supports and service options in their area. They also offer Family Caregiver Support Programs that assist family members as they are helping a loved one with dementia or other conditions. AAAs are sometimes known as "Aging and Disability Services" or "Aging and Long Term Care". The statewide network for AAAs is referred to as Community Living Connections (and will be referred to this way in the rest of this document). Visit ***www.waclc.org/connect*** or call 855-567-0252 to find your local office and more information.
- 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. Visit ***www.alzwa.org*** or call 800-272-3900.
- Another type of "guide" available in some areas, is a private geriatric care manager. They may be found through the Aging Life Care Association. Visit ***www.aginglifecare.org*** for more information.

Alzheimer's and dementia—what's the difference?

Dementia is a general term referring to a loss of cognitive function—remembering, thinking, and reasoning—severe enough to interfere with everyday life.

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

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

Terminology:

Throughout this document, a variety of terminology is used:

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

Wondering & Worried

"My husband has always been a forgetful kind of guy—it was when he started making up details about his own past because he could no longer remember them, that's when I started worrying. That's when we went to see the doctor."

– **Debbie H.**, family caregiver from Yakima

You may be wondering

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

What should you expect in this stage?

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

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

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

What you can do:

- Learn about normal changes with aging and those that indicate a need to get a check up. See the ***"10 Warning Signs"*** on page 21.
- Keep track of changes you notice. If your loved one doesn't bring it up, find the right time and a sensitive way to discuss these changes with them—get it out in the open.
- Ask your loved one to have a complete medical check-up. It's important to know if memory and thinking changes may be caused by something that could be treated or reversed. Even if not, its best to know what you're dealing with.
- If your loved one is resistant to a medical check-up, enlist the help of trusted family or friends who may be able to encourage this.
- Call and ask your loved one's health care professional for the Medicare Annual Wellness 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 loved one's current health care professional, try to find a new one. Most primary care professionals can diagnose dementia. But if you're looking for a specialist, contact the Alzheimer's Association to help identify providers in your area.
- If you know or suspect your loved one has hearing loss, get it checked and addressed—hearing loss makes it harder for a person with memory loss or confusion to communicate. This can lead to misunderstandings and social isolation.
- Make sure both you and your loved one are making healthy lifestyle choices:
  - Stay active and engaged in social groups, arts, and other activities of interest.
  - Eat fresh fruits and vegetables.
  - Be physically active.
- Make it a priority to begin and/or complete legal, financial and advance care planning, including essential planning documents. While all adults should have a plan in place in the event of one's disability or death, such planning is even more important for anyone beginning to experience changes in memory or thinking abilities. While such changes may or may not end up being dementia, it is critical to complete this planning while your loved one has the ability to do so.

Action Steps

The following steps are important at this point:

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

Mild Cognitive Impairment (MCI)

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

"We were concerned about Mom's memory long before we were able to get a diagnosis. The Alzheimer's Association was a great source of information and support. Even when there were no 'answers,' there was always understanding and encouragement from that community."

– Cindy B., family caregiver from Bellevue

You may be wondering

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

What should you expect in this stage?

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

They may forget details, display less ambition; may have emotions that go up and down, and be more reliant on you.

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

You may:

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

What you can do:

- If not yet evaluated, ask your loved one's health care professional for the Medicare Annual Wellness exam—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 to overall wellness and functioning.
- Learn more about Mild Cognitive Impairment.
- Consider keeping a notebook about your loved ones changes and needs.
- Tell your own health care provider that you are caring for a loved one with cognitive impairment so they can be aware of potential health-related risks.
- 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.
- Encourage a healthy lifestyle including regular exercise, a healthy diet, and social activities.
- Encourage the use of long-time skills, like playing the piano, singing, typing, crafts, or speaking a second language.
- Share (and read) the booklet—*"Living Well with MCI or Early Dementia"* from the Alzheimer's Association**.** See a link to this booklet in the ***Resource List*** on pg. 25 – 26.

Action Steps

The following steps are important at this point:

Remember! If your loved one has not yet had a medical assessment, contact their health care professional, a Geriatrician, a Neurologist, and/or a Neuropsychologist.

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

Early-Stage Dementia

"We were very fortunate that my parents signed important legal documents and had long-term care insurance in place from the beginning of mom's dementia. These things gave my dad peace of mind after mom could no longer make decisions."

– **Karen M.**, family caregiver from Seattle

You may be wondering

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

What should you expect in this stage?

Your loved one has difficulty accomplishing some activities. 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 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 that your loved one 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.
- Want to ask for help around the home like housekeeping, errands, laundry, or yard care.
- Be impressed by your loved ones 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 you're not happy with current care, find a health care professional that will work with you and your loved one together.
- Learn all you can about the disease and tips for communicating supportively with your loved one. See ***Communication Tips*** on pg. 23.
- 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 ***Resource List*** on pg. 25 – 26.
- 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.
- Explore how your loved one wants to live at the end of their lives. Learn about "having the conversation", through the *"Conversation Starter Kit for Families of Loved Ones of People with Alzheimer's Disease or other Forms of Dementia."* See ***Resource List*** on pg. 25 – 26.
- Encourage your loved one to use the in-depth dementia advance planning legal document in Washington State, *"Alzheimer's and Dementia Mental Health Advance Directive"* to document their wishes about anticipated challenges throughout the progression of the disease (such as when to stop driving, where they want to live, who provides their care). See ***Resource List*** on pg. 25 – 26.

Continued on next page...

What you can do (continued):

To help your loved one:

- Provide *"Living with Alzheimer's: Taking Action Workbook."* Find this in the ***Resource List*** on pg. 25 – 26.
- Go along on medical appointments if your loved one agrees. If they do not want this, try calling the practitioner ahead of appointments to share concerns.
- Create and stick to simple routines.
- Monitor that any medications are taken properly.
- Assist them to continue activities of interest.
- Promote the best functioning possible. Get hearing loss and vision checked regularly. Make sure hearing aids and glasses are in good condition and used as needed.
- Resist the urge to step in and do things for them; allow more time, and occasional errors.
- Encourage them to attend an early stage support group and seek out dementia-friendly recreation activities.
- Consider enrolling in a clinical trial or research study on dementia at a university or memory clinic. Your loved one may advance our understanding of dementia and help in the effort to develop new treatments.
- When you see behaviors that are "out of character," do NOT take these personally—recognize it's the disease.
- 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 you can 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 such as removing your loved one's credit cards (or lower credit limits) and other key wallet documents.

Services to consider:

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

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:

- **Community Living Connections** (Area Agency on Aging) for your area may be found at 855-567-0252 or www.waclc.org/connect
- **Alzheimer's Association** at 800-272-3900 or www.alzwa.org
- **Alzheimer Society of Washington**, serving Whatcom County 800-493-3959 or www.alzsociety.org

"My father really didn't want to be defined by the disease and wanted to LIVE his life in his own way as long as he could. We continued to keep him engaged with his favorite activities and people as we dealt with the acceptance of the changes that were coming in the future."

– Kim B., family caregiver from Bellingham

Action Steps

The following steps are important at this point:

See Action Steps on pages 7 and 9, and do the following:

- ❑ **If your loved one** is still driving, review together the booklet *"At the Crossroads: Family Conversations about Alzheimer's, Dementia and Driving"* which may be found in the ***Resource List*** on pg. 25 – 26.
- ❑ **Make sure your loved one** either carries ID or wears MedicAlert+Safe Return jewelry.
- ❑ **Discuss with your loved one** their wishes for end-of-life care, and document these as decisions are made.
- ❑ **Have a family meeting** to discuss what's happening and next steps, such as ways the family can support the person with memory loss to stay active, healthy and socially engaged, or help you with decisions and planning around driving or other safety concerns.
- ❑ **Make a back-up plan** to be used if something happens to you.
- ❑ **Consider Care Coordination or Case Management Services:** "Guides" for the journey, they can assist with each step. See more on pg. 5.
- ❑ **Contact the Alzheimer's Association/Alzheimer Society** for dementia related information, education and support opportunities.
- ❑ **Contact your local Community Living Connection and Family Caregiver Support Program** to find out more about local support services.

Mid-Stage Dementia

"When we arrived at mid-stage, we arranged for an agency to help my dad with mom's care. One of their care workers would come twice a week to help with cleaning or just sit with mom to do puzzles while my dad went to appointments and met with friends. Mom loved the care worker and my dad had time away to see friends and run errands."

– **Teri R.**, family caregiver from Vancouver

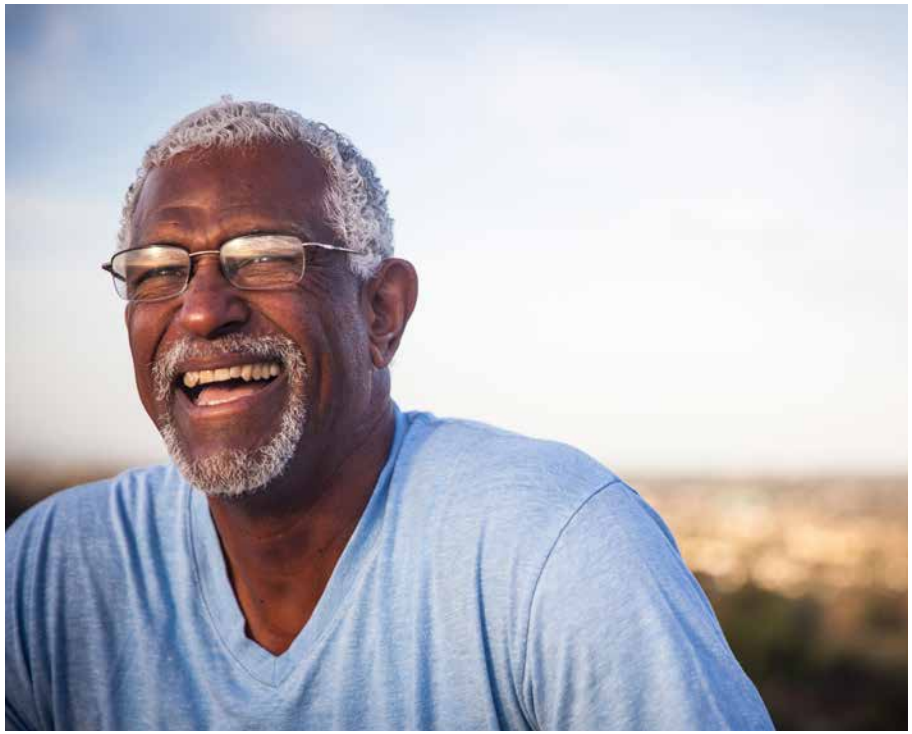
You may be wondering

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

What should you expect in this stage?

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

- Have more trouble with memory—such as recalling their own address or personal history.
- Have problems organizing, planning, allowing instructions and solving problems.
- Not recognize familiar people.
- Forget how to initiate routine tasks or how to complete them, including health and hygiene care.
- May resist bathing or other personal care. May 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
- Have 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 caregiver 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 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.

What you can do:

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

To help your loved one:

- Encourage family and close friends to learn communication tips and techniques—and to help provide activities your loved one still enjoys. Refer them to the Alzheimer's Association website or 24/7 toll-free Helpline: 800-272-3900.
- Try to provide kindness, understanding, and acceptance.
- Channel their energy—go for regular walks together, encourage them to help with chores like vacuuming, sweeping, folding laundry, gardening.
- Simplify tasks and activities, break into smaller steps—allow more time for your loved one to accomplish them.
- Reminisce—look at old photo albums, a memory book or old videos.
- Make sure your loved one gets ongoing medical care.
- If you notice any SUDDEN changes in behavior, call your loved one's physician—this can be a sign of an infection or other medical issue.
- Talk to their doctor about completing a 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" to find helpful tips on daily care such as activities, providing personal care and managing incontinence. Visit **www.alz.org/care** to learn more.

Services to consider:

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

- In-home care to assist with bathing, dressing, getting ready in the morning or evening, other personal care tasks/routines.
- Counseling to handle your own grief, depression and anger, and get emotional support.
- If you haven't looked into or used yet:
  - Powerful Tools for Caregivers
  - Support Group
  - Respite Care (in or out of the home)
  - Consultants who specialize in caregiving issues and can assist with behaviors
  - MedicAlert+Safe Return or GPS locator program
  - Behavior education and consultation, such as STAR-C

Contact your local Family Caregiver Support Program to inquire about local education and support services mentioned above. Find your local number here: **www.waclc.org/connect**.

Action Steps

See Action Steps on pages 7, 9, and 13 and do the following:

- ❑ **Request** a home safety evaluation with a Physical or Occupational Therapist to make the home safer and home care tasks easier.
- ❑ **Update** your back-up plan to be used if something happens to you.
- ❑ **Have** a family meeting to discuss what's happening now and ways to support your loved one and you, and any next steps as care needs increase.
- ❑ **If help with financing care is needed**, contact your local Community Living Connections or Home and Community Services office. Find these at ***www.waclc.org/connect***
- ❑ **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.

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 Washington state include adult family homes, assisted living facilities and nursing homes.

- Find out more, and what's available in your area: www.dshs.wa.gov/altsa

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

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

- **Community Living Connections** (Area Agency on Aging) for your area may be found at 855-567-0252 or www.waclc.org/connect
- **Alzheimer's Association** at 800-272-3900 or www.alzwa.org
- **Alzheimer Society of Washington**, serving Whatcom County 800-493-3959 or www.alzsociety.org

Late-Stage Dementia

"In the late stages we had hospice for my wife and it was a very important and meaningful experience for all of us. The respite and comfort that hospice provided was exactly what was needed. I wish we had reached out earlier when we could have benefitted from palliative care as well."

– **Todd L.**, family caregiver from Olympia

You may be wondering

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

What should you expect in this stage?

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

- Not recognize you or others by name. This does not mean they don't know (or feel) who you are.
- Have increasing difficulty communicating—may use "word salad" (mixed up words), or be speechless. Nonverbal communication may work best.
- Be frequently or totally incontinent.
- Experience changes in physical abilities including ability to walk, sit and eventually swallow.
- Have rigidity, immobility, jerks or seizures.
- Be feeling deep emotions and may scream, moan, or flail.
- Be vulnerable to infections, especially pneumonia.

At the same time, you may notice that they are still attuned to the emotions of others, enjoy companionship, respond to physical touch or music, and can encourage others to slow down and focus on the present.

You may:

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

What you can do:

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

"My husband is now in the very last stage of this disease, and it is now all about keeping him comfortable. I am not sure if he knows me or when I'm there, but I keep going because I do know him, and I hope that somewhere inside he knows we all love him, and that our visits continue to give him some comfort." – **Deborah J.**, family caregiver from Kennewick

To help your loved one:

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

Services to consider:

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

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

Reach out to others in a similar situation, a care coordinator, a counselor, the Alzheimer's Association or your local Community Living Connections for support.

- **Community Living Connections** (Area Agency on Aging) for your area may be found at 855-567-0252 or www.waclc.org/connect
- **Alzheimer's Association** at 800-272-3900 or www.alzwa.org
- **Alzheimer Society of Washington**, serving Whatcom County 800-493-3959 or www.alzsociety.org

Dementia Quick Reference

10 Warning Signs of Alzheimer's

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

For more information on "Other Dementias", go to: www.nia.nih.gov/alzheimers/topics/other-dementias

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 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.

Middle Stage Alzheimer's Disease

- Increasing needs for care and supervision.
- More trouble with memory—such as own address or personal history.
- Problems organizing, planning, allowing 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.
- Abilities that vary from one day to the next.
- 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, 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—may use "word salad" (mixed up words), or be speechless. Non-verbal 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

Dementia damages pathways in the brain. Brain changes make it difficult for a person with dementia to say what they want and understand what others are saying. Your loved one may have trouble coming up with the right words or a name, or may invent new words. At some point, they may repeat a question over and over. Because dementia changes communication skills gradually, a loved one's words may at times make little or no sense to you. He or she might also have trouble understanding your words. The resulting misunderstandings can fray nerves all around, making communication even more difficult.

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, 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.

Continued on next page...

What you can do (continued):

- **Keep it simple.** Use short sentences. Ask one question or offer one instruction at a time. It usually helps to use "positives"—say "Let's go here" vs. "Don't go there." As the disease progresses, ask questions that require a yes or no answer.
- **Allow time and be patient.** Slow pace of speech slightly and allow time for the person to process and respond. Try to avoid interrupting. If you're feeling rushed or stressed, take some time to calm down.
- **Focus on feelings.** Listen for the meaning behind the words. Their tone or body language may provide clues. Respond to the emotions.
- **Offer comfort.** If a person with dementia is having trouble communicating, let them know it's OK. Offer hugs, or hold 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. 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 Community Living Connections offices will know of such opportunities. Reach out today!

"As my mom declined she got really good at reading my facial expressions and body language rather than understanding my words. I needed to always calm and center myself before each visit so the she would be calm too."

– Lynne W., family caregiver from Tumwater

Resources Mentioned in the Document

ORGANIZATIONAL WEBSITES

- Aging Life Care Association (for private geriatric care management services): **www.aginglifecare.org**
- Alzheimer's Association: **www.alz.org** or **800-272-3900**
- Alzheimer's Association Washington State Chapter, Serving Washington and Northern Idaho: **www.alzwa.org** or **800-272-3900**
- Alzheimer Society of Washington (Whatcom County): **www.alzsociety.org** or **360-671-3316** or **800-493-3959**
- Alzheimers.org: **www.alzheimers.gov**
- Community Living Connections (Area Agencies on Aging/AAAs): **www.waclc.org/connect** or **855-567-0252**
- Eldercare Locator (Administration on Aging): **www.eldercare.gov** or **800-677-1116**

INFORMATION AND DOCUMENTS

- At the Crossroads: Family Conversations about Alzheimer's, Dementia and Driving: **www.hartfordauto.thehartford.com/UI/Downloads/Crossroads.pdf**
- Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging: **www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide**
- Communication: Tips for Successful Communication During All Stages of Alzheimer's Disease: **www.alz.org/national/documents/brochure_communication.pdf**
- Dementia and Driving Issues: **www.alz.org/care/alzheimers-dementia-and-driving.asp**
- Home Safety for People with Alzheimer's Disease: **www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease/introduction**
- Living Well with MCI or Early Dementia: **www.alz.org/documents/mndak/alz_living_well_workbook_2011v2_web.pdf**
- Living with Alzheimer's—Taking Action Workbook: **www.alz.org/i-have-alz/downloads/lwa_pwd_taking_action_workbook.pdf**
- MedicAlert+Safe Return: **www.alz.org/care/dementia-medic-alert-safe-return.asp** or **888-413-3768**
- Safety Concerns for People with Dementia—An Info Kit: **go.usa.gov/x5ESt** or by visiting **www.dshs.wa.gov/altsa/dementia-action-collaborative**

RESOURCES FOR LEGAL AND ADVANCE CARE PLANNING

- 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—about the care they want, and the care they don't want. It is designed to be used in the early stages of dementia. **www.theconversationproject.org/wp-content/uploads/2016/05/TCP_StarterKit_Alzheimers.pdf**
- End of Life Washington—Offers information about the in-depth planning document "Alzheimer's and Dementia Mental Health Advance Directive", end-of-life choices, advance directives, choosing a health care agent and on Physician Orders for Life-Sustaining Treatment (POLST): **www.endoflifewa.org**
- Honoring Choices, Pacific Northwest—Offers information about various end-of-life choices: **www.honoringchoicespnw.org/learn/know-your-options**
- Northwest Justice Project—Offers free information, videos and self-help packets including forms for Powers of Attorney and Advance Directives: **www.washingtonlawhelp.org/issues/aging-elder-law/powers-of-attorney-health-care-directives**
- Washington Academy of Elder Law Attorneys—Offers a directory of elder law attorneys for those seeking advice or representation: **www.waela.org/directory**

RESOURCES ON OTHER DEMENTIAS

- Alzheimer's Disease Education and Referral Center, National Institute on Aging: **www.nia.nih.gov/health**
- The Association for Frontotemporal Degeneration: **www.theaftd.org**
- Frontotemporal Disorders: Information for Patients, Families and Caregivers: **catalog.ninds.nih.gov/ninds/product/Frontotemporal-Disorders-Information-for-Patients-Families-and-Caregivers/17-AG-6361**
- Lewy Body Dementia Association: **www.lbda.org**
- Lewy Body Dementia—Information for Patients, Families and Caregivers: **catalog.ninds.nih.gov/ninds/product/Lewy-Body-Dementia-Information-for-Patients-Families-and-Professionals/15-7907**

Action Steps Summary

- ❑ **Obtain a medical assessment** of memory loss/cognitive impairment and diagnosis for your loved one—this opens the door to necessary planning. This process should start with your health care practitioner, and may involve other specialists such as a Geriatrician, a Neurologist, and/or a Neuropsychologist
- ❑ **Contact the Alzheimer's Association** or Alzheimer Society of Washington (Whatcom County) for information and support.
- ❑ **Contact your area's Community Living Connections** (Area Agency on Aging/Family Caregiver Support Program).
- ❑ **Complete health care planning documents.** Your loved one should have:
  - A Health Care Directive (also called a "living will" or "advance directive" regarding treatment preferences); and
  - A Durable Power of Attorney for Health Care, appointing a health care "agent."
- ❑ **Complete a General Durable Power of Attorney document.** In this document, your loved one appoints an "agent" to assist with financial and related matters.
- ❑ **Complete an estate plan.** Your loved one's estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- ❑ **Consider Care Coordination** or Case Management Services: "Guides" for the journey, they can assist with each step.
- ❑ **Complete end-of-life planning** and document how your loved one wants to live at the end of their life, including medical care wanted or not wanted, comfort measures, and palliative and hospice care.
- ❑ **Discuss with loved one the issue of when to discontinue driving.** If needed, enlist help of healthcare provider, a professional driving evaluation, or call the Alzheimer's Association for more ideas.
- ❑ **Make sure your loved one either carries ID** or wears MedicAlert+Safe Return jewelry.
- ❑ **If help with financing care is needed**, contact your local Community Living Connections or Home and Community Services offices. Find these at ***www.waclc.org/connect***.
- ❑ **Have family meetings** along the way to discuss what's happening, and how to support the person with memory loss and care partner. Important topics of discussion include:
  - Encouraging a diagnosis; Discussing safety issues, such as driving and safe medication use;
  - Needing support with financial or legal planning;
  - Coordinating care at home;
  - Considering safe living situation and options;
  - Discussing ways to support the primary care partner/caregiver.
- ❑ **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 back-up plan** along the way to be used if something happens to you.
- ❑ **Discuss and seek palliative care** and hospice care.
- ❑ **Talk to health care professional** about establishing a Physician's Order for Life Sustaining Treatment (POLST) when appropriate.

DESIGN: Dandy Co. dandy-co.com

The Dementia Action Collaborative

The Washington State Plan to Address Alzheimer's Disease and Other Dementias was published in January 2016. It identifies goals, strategies and recommendations to prepare for the future. The plan also called for the formation of a next generation workgroup to implement the recommendations. This group is known as the Dementia Action Collaborative (DAC)—a statewide collaboration of public-private partners committed to implementing recommendations in the plan. The DAC includes a range of appointed members—people with dementia, family caregivers, advocates, representatives of the aging network, Alzheimer's organizations, long-term care providers, health care professionals, legislators and governmental agencies. Find out more about the DAC and their activities at:

www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan

Dementia Action Collaborative
Washington State

This publication is a new resource; we welcome your feedback. If you have suggestions, please email them to: Dementiaroadmap@dshs.wa.gov

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