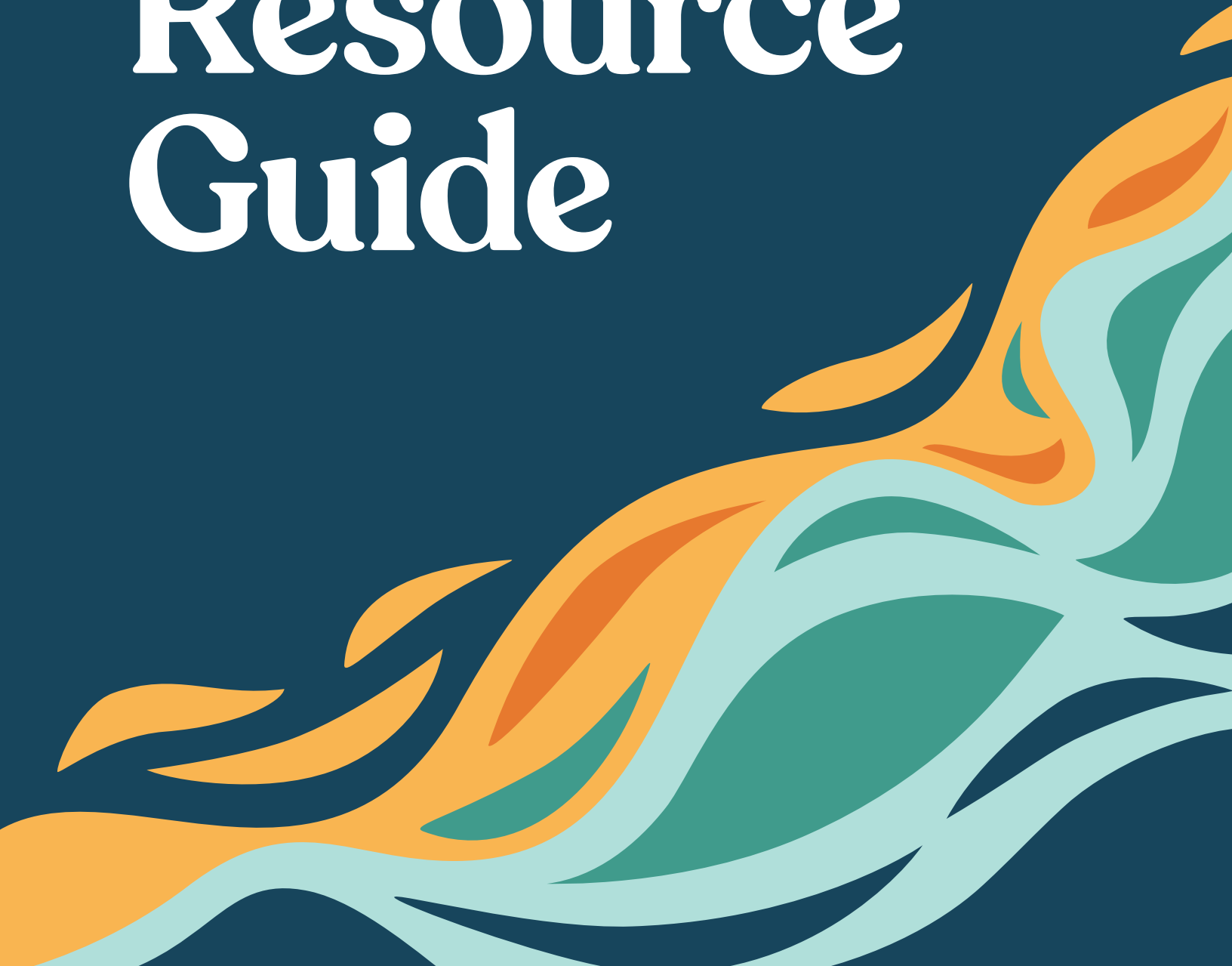


The logo for the Alaska Dementia Action Collaborative is located in the top left corner. It consists of a white rectangular box containing the text "Alaska Dementia Action Collaborative" in a white, sans-serif font. Above the text, there are stylized, flowing shapes in shades of orange, yellow, and teal, resembling waves or abstract foliage.

Alaska
Dementia Action
Collaborative

Caregiver Resource Guide

A large, decorative graphic on the right side of the cover features stylized, flowing shapes in shades of orange, yellow, and teal, similar to the logo in the top left. These shapes appear to be waves or abstract foliage, set against a dark blue background.

Thank you!

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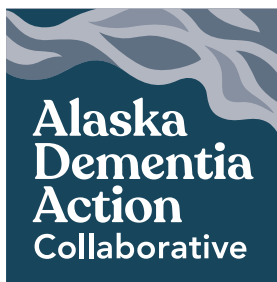
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Overview of the Journey Described in this Guide:

1

Worried and Wondering

- I'm seeing changes. Should I be more worried?
- Is this memory loss something more than normal aging?
- Where do we go for answers or who can I talk to?
- Should the person I'm concerned about have a memory screening?

2

Definitely Concerned

- Will these memory issues or changes get worse?
- Are there things I can do to support good brain health?
- When should I try to find a specialist?
- Where can I go to find more information, resources?
- Should I talk with a doctor about the person's memory concerns?

3

Obvious Changes: Now What?

- What can be done to maintain a healthy brain?
- Should I be worried about safety, like driving?
- What do we need to plan for?
- How can I help the person living with dementia stay connected and involved?

4

I Need More Help

- I'm tired – how can I get a break?
- How do I respond to the person's day-to-day challenges?
- What changes can I make in our home to help with independence and safety?
- How do I prepare for increasing care needs?

5

Acceptance and Support

- How do I make sure people are taking good care of the person's needs when I'm not there?
- Where is the best place for the person to live?
- What is my role at this stage?
- What does medical and daily care look like at this point?

How to Use this Guide

Everyone is different – the journey for people with dementia and the people providing care will be unique. People have different preferences – some of us want to talk with a professional who provides guidance and some of us want to know where to look on the Internet for information, while others want to connect with people who are currently caregivers and can share stories and provide mutual support.

This Guide offers the following:

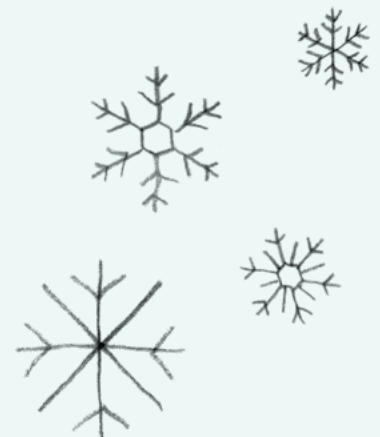
- Names and contact information for organizations (both Alaska-based and some nationwide) that provide information and support services
- General information on topics like Technology and Financial Planning
- Stages of the Disease: For each stage, details on what to expect, how to respond, services and resources* specific to that phase. The information provided on each stage is just a brief snapshot and is not meant to be a comprehensive description. In addition, the disease stages are not black and white; people may experience symptoms at different stages.

**Services are more general descriptions of options to consider, resources include specific details such as phone numbers and web addresses.*

Everyone's experience is different – like snowflakes ...

It's a marathon, not a sprint. Teepa Snow's gems are much better than the stages – he's a Ruby today and a Pearl yesterday. Each one is like a snowflake; you can't pigeonhole them into a textbook definition. You might meet someone who's been taking care of someone for months and years, but their experience may be totally different. It is what it is when it happens.

– Valerie, family caregiver in Anchorage



Who is this Guide for?

This guide is for care partners – family members, friends, neighbors – who care about someone with Alzheimer’s Disease and Related Dementia. Some but not all of the resources shared have eligibility requirements such as income-based or level of disability.



What is Alzheimer's Disease? What is Dementia?

Dementia is a general term that describes a group of symptoms associated with a decline in memory, reasoning, or other thinking skills. Many different types of dementia exist, and many conditions cause it. While dementia is more common as people get older, early-onset Alzheimer's Disease or Related Dementia can affect people in their 40s and 50s or in the rare occasion, in their 30s. 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.



Where to Start



Alzheimer's Resource of Alaska

Alzheimer's Resource of Alaska

Alzheimer's Resource of Alaska (ARA) is the only Alaska-based nonprofit that focuses solely on Alzheimer's Disease and Related Dementia. It was started in 1980 by two sisters who learned there weren't many resources for family caregivers when they were caring for their mother with dementia. The organization has grown into a statewide organization that provides individual consultations, free memory screenings, information, training, support groups and care coordination. ARA also maintains Community Resource Guides for different regions of Alaska that lists organizations and individuals that provide a range of services for people living with Alzheimer's Disease and Dementia.

907-561-3313/1-800-478-1080 | www.alzalaska.org



Alaska's Aging and Disability Resource Centers

Alaska's Aging and Disability Resource Centers (ADRCs) connect people with Alzheimer's and Related Dementia and caregivers with long-term services and supports of their choice. The ADRC network serves Alaskans statewide, regardless of age or income level, through regional sites.

ADRCs are part of a federal effort to help people more easily access the long-term services and supports available in their communities. That might include transportation, assistive technology, or in-home care.

The ADRC goal is to be a trusted resource. ADRC specialists counsel callers and visitors on long-term supports that fit their circumstances. People choose which services they would like, then the ADRC specialists help people access those services.

1-855-565-2017 | <https://dhss.alaska.gov/dsds/Pages/adrc/default.aspx>

Aging and Disability Resource Centers in Alaska



ADRC North: Fairbanks Senior Center

LINKS

Municipality of Anchorage

Bristol Bay Native Association

Independent Living Center (ILC)

Southeast Alaska Independent Living Center (SAIL)

SECTION 1

Worried and Wondering

When The Light Went On ...

My husband was a family counselor; he taught me about active listening and having the person repeat back what you said. I first started noticing that I would say something to him, and he would repeat back something totally different from what I said. Then he went to visit his family without me. Later they called and asked if something was wrong – he had taken the car, in a town he had lived for most of his life, and got lost. For several hours he couldn't find the car. That's when the light went on for me.

– Valerie, family caregiver in Anchorage



What you may be experiencing

You may notice subtle changes with the person. You or the person living with dementia may be concerned, but other people are likely not noticing.

Examples of changes:

- A change in personality – the person isn't as attentive or is more moody or irritable
- The house isn't as clean
- Less concern about personal hygiene or grooming
- Less involvement with activities and friends
- More or less talkative
- Less organized about finances

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 and Symptoms of Alzheimer's Disease in the box.
- Keep track of changes you notice. This may be helpful when meeting with a medical provider or other specialist later.
- Ask the person you're caring for to have a complete medical check-up. Are memory and thinking changes being caused by a health issue that can be treated? If the person is resistant to a medical check-up, enlist the help of trusted family or friends who may be able to encourage this.
- If the person you're caring for is on Medicare, ask for the Medicare Annual Wellness exam. Let the medical provider know what you've noticed either in person or in a letter.
- If you don't feel comfortable with the person's current health care

10 Warning Signs and Symptoms of Alzheimer's

- 1 *Memory loss that disrupts daily life*
- 2 *Challenges in planning or solving problems*
- 3 *Difficulty completing familiar tasks*
- 4 *Confusion with time or place*
- 5 *Trouble understanding visual images and spatial relationships*
- 6 *New problems with words in speaking or 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 and personality*

professional, look for a new one. Most primary care professionals can do a screening and then refer you to a specialist.

- If the person you are caring for has hearing loss, address this—hearing loss makes it harder for a person with memory loss to communicate.
- Make sure both you and the person you are caring for are making healthy lifestyle choices:
 - *Stay active in social groups, arts, and other activities of interest.*
 - *Eat fresh fruits and vegetables or Native foods.*
 - *Be physically active.*
- Make it a priority to complete legal, financial, and advance care planning documents. This planning is very important for anyone beginning to experience changes in memory or thinking abilities. There are self-guided planning tools or specialists who can assist. See [page 36](#) for financial planning information.



Services to consider

- **A free memory screening with a dementia consultant at Alzheimer's Resource of Alaska**

- **A meeting with a financial planner and/or elder law specialist**



Resources

- **Alaska Legal Services:** 1-888-478-2572 or www.alsc-law.org

- **Financial Planning for Long-Term Care Workbook by Marietta Hall:** www.apcm.net or email: marietta@apcm.net

- **Advanced Directive information: Five Wishes** (www.fivewishes.org) or **Alaska Advanced Directive** (www.caringinfo.org/wp-content/uploads/Alaska.pdf)

- **Alaska Power of Attorney:** courts.alaska.gov/shc/family/docs/poa-booklet.pdf

SECTION 2

Definitely Concerned

Pushing For Answers

I've had to push for a diagnosis. Four years ago my husband had a doctor's appointment. He was having memory problems and asked for an assessment. The doctor never shared the results. Three years later it was more obvious. I had to push for a full-blown neuropsych exam – this only happened after many calls, including to the director of the healthcare provider. By the time he was diagnosed with Alzheimer's he had major neurocognitive decline. That's when we found out he had been diagnosed with MCI (Mild Cognitive Decline) three years earlier – I wish I had known. We lost three years.

– Sharon, family caregiver in Anchorage



The person living with dementia is still independent but may have difficulty paying bills, preparing meals, shopping, or driving. They may forget details, display less motivation, may have emotions that go up and down, and be more reliant on you.

More noticeable changes are occurring, especially in personal hygiene or grooming.

What you may be experiencing

- You may feel irritation with changes in the person's moods.
- Also feel compassion for the person's changes.
- Find that other friends and family don't notice changes in the person you are caring for or understand your concerns.
- You may be asking yourself these questions:
 - *Will these memory issues or changes get worse?*
 - *Are there things I can do to help a person's memory?*
 - *When should I try to find a specialist?*
 - *Where can I go to find more information and resources?*
 - *Should I talk with a doctor about memory concerns?*

What you can do

- Become educated about dementia.
- Your health is important – you need to take care of yourself so you can support the person living with dementia.
- Attend medical appointments with the person if they agree (virtually if you are not in the same state). Consider calling the practitioner ahead of appointments to share concerns. Secure a durable Power of Attorney as soon as possible; this allows medical providers to share protected health information about the person with you.

Worth the Hassle

Dad was really not Dad anymore; things are way different. He had just lost his wife of 65 years, is that it? I reached out to his doctor and asked for cognitive testing – and sure enough, he was diagnosed with dementia. It was a hassle to make it happen - I was able to speak to my dad's doctor before his appointment but only after breaking through the system to reach a manager level. Just lucky and got the right person."

– **Maureen, Anchorage-based long-distance family caregiver**



- Begin or continue to keep a notebook about the person's changes and needs.
- Instead of thinking that the person should just "try harder" – remind yourself that they are doing the best they can.
- Do activities like paying bills or shopping together so the person living with dementia can have successes. If they become frustrated, suggest that they supervise.
- If the person has additional chronic conditions such as heart conditions, high blood pressure or diabetes, support them with managing these conditions. This may include helping with medications.

● ***If you and the person have not completed the advance care planning process, now is the time while the person can still participate.***

- Encourage lifestyle changes that may be helpful to overall wellness and functioning (see sidebar).
- Discuss when to discontinue driving.

Brain Wellness Strategies: these actions may slow the progression of the disease.

- 1 Get Moving:** *Physical activity everyday.*
- 2 Eat Healthy:** *Foods such as fish, whole grains, brightly colored fruits and vegetables and certain spices.*
- 3 Exercise The Mind:** *Activities that are mentally stimulating, like playing an instrument, reading or games or Alzheimer's Resource of Alaska's Mind Aerobics program (see information below).*
- 4 Focus on the Positive:** *Make time for something fun every day, be social, and laugh.*
- 5 Reduce Stress:** *Try meditation, yoga or walks.*
- 6 Find Meaning and Purpose:** *Re-think priorities and dig into what's important.*
- 7 Keep Relationships Strong:** *Schedule regular lunch dates or walks, join a new group, or make plans to visit a relative.*
- 8 Manage Your Health:** *Regular doctor's appointments, plenty of sleep, limit alcohol and carefully manage medications.*
- 9 Establish a Routine:** *Create a calendar with set times for daily activities and weekly activities.*



Services to consider

- **Education, education, education** – seek out trainings, resources, online videos/blogs/social media groups to get familiar with what to expect
- **Technology to assist with memory** including reminder apps or smart pillboxes. See [page 38](#) for information on Technology.



Resources

- **Information on Alzheimer’s Disease and Related Dementia:**
 - Alzheimer’s Resource of Alaska: www.alzaska.org/education
 - National Alzheimer’s Association: www.alz.org/help-support
 - Teepa Snow/Positive Approach to Care: www.teepasnow.com/resources
 - Dementia Careblazers: www.careblazers.com
- **Managing medications:**
www.nia.nih.gov/health/managing-medicines-person-alzheimers
- **Wellness workbook:** Living Well with MCI or Early Dementia provides wellness steps, discussion guides and action plans:
www.alz.org/media/mnnd/documents/18_alz_living_well_booklet.pdf
- **For guidance on driving discussions:** At the Crossroads: Family Conversations about Alzheimer’s Disease, Dementia and Driving: https://s0.hfdstatic.com/sites/the_hartford/files/at-the-crossroads-2012.pdf
- **Brain Healthy Activity - Mind Aerobics:**
www.alzaska.org/mind-aerobics
- **Alaska Power of Attorney:**
courts.alaska.gov/shc/family/docs/poa-booklet.pdf

SECTION 3

Obvious Changes – Now What?

A Zigzag Journey

I find the straight path in the zigzag journey of dementia. That's the way it is. Every day is different. One of the hardest questions for me to answer is how are you and how is Jim? I can say "for right now, this is how it is ..." You never know because it changes all the time.

– Deborah, Delta Junction



The person living with dementia is beginning to have noticeable difficulties with some activities, especially when trying to multi-task. This person may need more time to process information.

Other changes you may notice include:

- Trouble with time or sequence of events
- Forgetting names of familiar people and things
- Decreased performance in work or social situations
- Writing reminders and then losing them
- Increased preferences for familiar things
- Significant mood and/or personality changes including feelings of sorrow, suspicion, anger, or frustration
- Increasing indifference to everyday courtesies like greeting people, saying thank you, etc.
- More trouble driving safely

You may find that the person remembers some things very well, especially stories from long ago. And at the same time, they may be able to focus more on the present moment, enjoy humor and be more creative.

What you may be experiencing

- You may feel optimism and/or an early sense of loss and grief
- Notice a need to provide more reminders and support to the person
- Feel the need for help with household chores or errands
- Be impressed by the person's ability to adapt and grow in the midst of challenges
- You may be asking yourself these questions:
 - *What can we be doing to improve the person's memory?*
 - *Should I be worried about safety, like driving?*
 - *What do we need to plan for?*
 - *How can I help the person living with dementia stay connected and involved?*

What you can do

- Get training for yourself on how to be a caregiver for someone with dementia. Alzheimer's Resource of Alaska offers a six-week course called "The Savvy Caregiver" specifically for friends and family members providing care to a person living with dementia.

- 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 the person together.
- Encourage the person to attend an early-stage support group and seek out dementia-friendly recreational activities.
- Look for ways to modify the person's favorite activities rather than give them up.
- Learn all you can about communicating supportively with the person living with dementia. See Communication Tips on [page 34](#).
- Share what you are learning about Alzheimer's Disease and Related Dementia with family and friends.
- Consider putting home safety measures in place such as removing tripping hazards or moving items so they are easy to reach.
- If the person living with dementia is still driving, enlist the help of their health care provider for support or call Alzheimer's Resource of Alaska for additional assistance.
- Consider ways to protect yourself and the person from financial missteps and exploitation such as removing the person's credit cards or lowering credit limits.
- Prioritize your well-being so you can sustain support of the person living with dementia:

Seeking Peaceful Days

I have two goals every day: The first is that he goes through a day without escalation or conflict. I make sure his days are peaceful. The second is that I maintain peace in my home. My home has to be my haven as well as his.

– **Deborah, Delta Junction**



- Explore how the person wants to live at the end of their lives, understanding they will need increasing amounts of care. Be careful about not making promises that may become impossible to fulfill.
- If the person's ability to do daily tasks has declined, ask the person's primary care physician for an occupational therapy (OT) evaluation. An OT will develop individualized goals to maximize safety and independence and improve your ability to help.



Services to consider

- **Consultation with a dementia education specialist through Alzheimer's Resource of Alaska (ARA)**

- **Educational workshops**

- **Online support groups**

- **Occupational therapy**

- **Intake with Aging and Disability Resource Center**

- **Technology to assist with daily living, organizing information**



Resources

- **Healthy Brain Activities - Living with Alzheimer's: Taking Action Workbook:** www.alz.org/getmedia/da9e2ce1-d73c-437a-be7c-d5761afd06e9/taking-action-workbook

- **Dementia Minds is a national organization for people living with Alzheimer's Disease:** www.dementiaminds.org

- **Home Safety**
 - www.nia.nih.gov/health/home-safety-and-alzheimers-disease
 - AARP's HomeFit Guide: www.aarp.org/livable-communities/housing/info-2020/homefit-guide.html

- **Financial Planning for Long-Term Care Workbook by Marietta Hall:** www.apcm.net or email Marietta Hall at marietta@apcm.net

Resources Continued...

- **Alzheimer's Resource of Alaska Savvy Caregiver Course:**
www.alzalaska.org/savvy-caregiver

- **Resource for talking with the person living with dementia: Conversation Starter Kit for Families of Loved Ones of People with Alzheimer's Disease or other Forms of Dementia:**
www.theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf

- **Well Haven Occupational Therapy specializes in dementia and provides services statewide via telehealth:** www.well-haven.com

- **Online Peer Support Options**
 - ALZConnected online community: www.alzconnected.org
 - Facebook groups
 - [Alzheimer's Resource of Alaska Caregiver Support Group](#)
 - [Oh Hello Alzheimer's](#)

- **Caregiven - an app that offers a centralized place to store medical information, team member contacts and critical documents:**
www.caregiven.co

- **Assistive Technology of Alaska – provides free consultations and resources:** www.atlaak.org

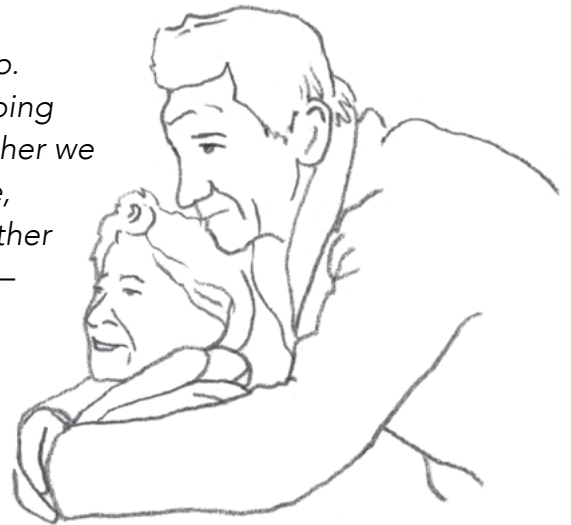
SECTION 4

I Need More Help

Good News And Bad News

The Bridge Adult Day Program has been a big help. I thought she would hate it and ask “what am I doing here?” The good news – we started going, I told her we were volunteering at first, and she does really well there, the staff are kind and nice, she doesn’t notice that the other people there are pretty low in their abilities. Bad news – she is less and less aware. When I come to pick her up, she’s happy to see me but doesn’t ask where I have been. It does give me a break.

-Adrian, family caregiver in Juneau



In this stage, the confusion becomes more obvious and the person living with dementia will have increasing needs for care and supervision.

Areas of concern you may experience:

- **Communication:** difficulty finding words, expressing thoughts or following conversations. May swear uncharacteristically.
- **Behavior:** changes such as depression, anxiety, irritability or clinginess as well as verbal or physical outbursts, wandering and difficulty sleeping
- **Daily Care Needs:** eating, dressing and grooming become more challenging including possibly resisting bathing or periods of incontinence
- **Safety:** at this point the person cannot be left alone safely

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. Seek out moments of joy.

What you may be thinking

- I'm tired – how can I get a break?
- How do I respond to the person's day-to-day challenges?
- What changes can I make in our home to help with independence and safety?
- How do I prepare for increasing care needs?

What you can do:

- Plan ahead for the person's increasing care needs - either in-home care or a long-term care facility. This is a personal decision; there is not one right answer.
- Establish or maintain routines for you and the person.
- Practice not taking communication changes personally – it's the disease. The disease begins to be louder than the person.



Things Don't Have To Be Right

I made the change from working with reason to working more on emotions. I discovered that it didn't help to try to straighten things out, it only made her frustrated and angry with me for disagreeing with her – things don't have to be right. For example, my wife would call our daughter, who just had her first baby, her sister (who is 73). But there wasn't any point to straightening her out. I knew she was talking about our daughter – it didn't make a difference to her.

-Adrian, family caregiver in Juneau

- Ask for help taking care of the home or providing care: housekeeping, errands, yard care, handy person, or in-home assistance.
- If you get unwanted opinions, recognize that others may be trying to help – see if you can work out a plan for them to assist in some way.
- Emotional support is critical. Attend a support group or seek out one-on-one counseling.
- Lock up or remove dangerous items from the home. You also may need to put away things like toothpaste, lotions, shampoos, or soap.

To help the person living with dementia:

- Encourage family and close friends to learn how to communicate and to help provide activities the person still enjoys.
- Channel the person's energy – go for regular walks together, encourage help with chores like vacuuming, sweeping, folding laundry, or gardening.
- Simplify tasks by breaking them into smaller steps and allow more time.
- Reminisce with the person by looking at photo albums or old videos.
- Make sure the person gets ongoing medical care.
- If you notice any SUDDEN changes in behavior, call the person's physician – this can be a sign of an infection or other medical issue.

- If you haven't already, talk to their doctor about completing a Physician Orders for Life-Sustaining Treatment (POLST) form. Unlike an Advanced Directive, POLST is for people with advanced illness and is focused on treatment options. It is signed by a physician and becomes a medical order.



Services to consider

- **Caregiving services - Your local Aging and Disability Resource Center can help you in learning what's available and how to access it. Possible services include:**
 - Adult Day Care: a center that provides supervision, social opportunities and basic care during daytime hours.
 - In-Home/Respite/Home Health/Personal Care: these services are provided in the person's home, typically as-needed (not round-the-clock).
 - Assisted Living: a licensed home or facility that provides 24-hour supervision and assistance as needed
 - Nursing Home: a facility that provides skilled medical care
- **If the person is a veteran, contact the VA's Caregiver Support Program to learn what options are available. You, friends or family members may be eligible to be paid to provide care through the Veterans-Directed Care Program.**
- **Counseling or a caregiver group to get support with managing your own grief, depression and anger. Alzheimer's Resource of Alaska can help connect you.**
- **Technology options may include a monitoring device if the person wanders or Zinnia TV which provides programming specifically designed for people with dementia.**



Resources

- Alzheimer's Resource of Alaska provides training on long-term care options.

- The ABC's of Choosing a Long-Term Care Facility is available on the Long-Term Care Ombudsman's Resource Page (akoltco.org/helpful-resources).

- Information on POLST available here: www.akpolst.org

- Alzheimer's Association's online "Caregiver Center" has helpful tips on daily care such as activities, providing personal care and managing incontinence: www.alz.org/help-support/caregiving

- Aging and Disability Resource Center (ADRC). Find out which ADRC serves your community: 1-855-565-2017, dhss.alaska.gov/dsds/Pages/adrc/default.aspx

- See [page 32](#) for Veterans'-specific resources

SECTION 5

Acceptance and Support

Space to Breathe

I have a neighbor and if I need to, I can go next door and say I just need a break. And she would say OK and fix me a cup of coffee. It doesn't need to be long. Or sometimes I go to the bathroom and shut the door. We all need our space just to breathe.

– **Peggy, family caregiver in Anchorage**



In this stage, the person living with dementia is completely dependent for personal care activities. This is also described as the “end of life” stage.

The person may:

- Not recognize you or others by name. This doesn't mean they don't sense who you are.
- Have increasing difficulty communicating – may use “word salad” (mixed up words) or be speechless. Nonverbal communication like touch may work best.
- Be incontinent.
- Experience changes in physical abilities including ability to walk, sit and eventually swallow. They will likely use a wheelchair and spend a significant amount of time in bed.
- Be feeling deep emotions and may scream, moan or flail.
- Be vulnerable to infections, especially pneumonia.

At the same time, you may notice that he or she is still attuned to the emotions of others, enjoys companionship, responds to physical touch or music, and can encourage others to slow down and focus on the present.

What you may be experiencing or thinking:

You may be experiencing profound grief as you become aware that the end-of-life for the person living with dementia near. You may find that friends and family are also experiencing grief.

Questions you may have:

- How do I make sure people are taking good care of the person when I'm not there?
- Where is the best place for the person to live? What are the in-home and or out-of-home/residential care options in my community?
- What is my role at this stage?
- What does medical and daily care look like at this point?

What you can do:

- Consider what kind of emotional support you may want or need during the period near and after death.
- Allow plenty of time for tasks and activities – don't rush.
- Be together in ways that don't require words.
- Actively seek palliative and/or hospice care.
- Review with the person's health care professional any health issues and related medications that could be reduced or discontinued.

- Schedule a family discussion about end-of-life plans that have been made or to discuss decisions that need to be made. Hospice can help facilitate this discussion.
- If the person is living outside of his or her home, you should be welcomed to that facility. If you have concerns about the person's care, share these with the facility's administrator or case manager.
 - *If you're worried about the person's care or safety and do not feel like your concerns are being addressed, contact the Long-Term Care Ombudsman at 907-334-4480 or Adult Protective Services at 1-800-478-9996.*

To help the person living with dementia:

- Maintain simple, consistent routines with a mix of rest and activity.
- Recall important life events or achievements using photos or videos.

Family photos

He's become very tender in a lot of ways. He's much more emotional than he used to be, he gets teary eyed more often. Like he sees a picture of his family – an old picture of he and his brothers. He doesn't remember that his brother passed away – he talks about missing Tim and wanting to visit with him. It's hard – I just say "We'll do that later" and then he forgets about it.

– **Peggy, family caregiver in Anchorage**



- Think about the person's core interests in their life; consider music, smells, flavors or textures – for example, flowers, traditional foods, or comfort items like stuffed animals or soft blankets.
- Encourage other family and friends to visit on a regular basis.
- Even though the person may not be verbal or ambulatory, he or she will still appreciate kind words, loving hugs, and comfort.



Services to consider

- **Nursing Homes:** licensed by the state of Alaska to provide skilled medical care to people who meet the eligibility for this level of care. Ask about specific units dedicated to memory care.

- **Hospice Care:** intended to support a person staying at home as long as possible and focused on managing pain and symptoms and supporting caregivers.

- **Support group, counseling or other emotional support for yourself**



Resources

- The Aging & Disability Resource Center serving your area will help with access to services including hospice providers.

- Alzheimer's Resource of Alaska coordinates caregiver groups as well as assisting with access to counseling support.

- Hospice of Anchorage's Resource Center is open to anyone, not just Anchorage residents. The Resource Center has a Dementia Care Library with items such as robotic pets, music players and fidget blankets. While shipping is not available, caregivers are welcome to stop by when they are in Anchorage to pick up helpful items. Call or visit for more information: 907-561-5322, hospiceofanchorage.org/resources

For Veterans

Veterans and family members have several access points for services and support including:

- VA Community Medical Provider
- Veteran Service Organizations
- Alaska Office of Veterans Affairs
- Alaska VA Caregiver Support Program

Possible services through the VA

- **Homemaker Home Health Aide Program:** *Provides a trained person who can come to a Veteran's home and help the Veteran take care of themselves and their daily activities.*
- **Outpatient Respite:** *pays for care for a short time when family caregivers need a break.*
- **Adult Day Services:** *Veterans can go to a center during the day for social activities, peer support, companionship, and recreation.*
- **Veteran Directed Care Program:** *Veterans hire their own workers (often family members) to meet their daily needs to help them live at home. This program is currently available in the Kenai, Kodiak, Southeast, and Mat-Su regions.*

Local Veteran Service Organizations (VSOs) can assist veterans with accessing benefits. For more complicated needs, the Office of Veterans Affairs is a good contact.

In addition, Alaska has a VA Caregiver Support Program based in Anchorage that serves the entire state.

Important Contact Information for veterans and their family members

- **List of local Veteran Service Organizations, including Alaska Tribal Veteran Representatives:** veterans.alaska.gov/veterans-service-organizations
- **Alaska Office of Veteran's Affairs:** alaska.veterans@alaska.gov, 888-248-3682 (Toll Free) or 907-334-0874, veterans.alaska.gov/home
- **Alaska VA Caregiver Support Program:** 907-375-2606

Additional Information

- **AK VA guide:** veterans.alaska.gov/media/2062/state-veterans-benefits-booklet-2020-optimized.pdf
 - **National Caregiver Support Line:** 1-855-260-3274 (Toll Free)
-

For Long-Distance Caregivers

- Find specific staff you can trust to help you monitor care.
- If possible, develop a network of locals, family or friends who are willing to be your eyes and ears.
- Use technology whenever possible.
- Watch for warning signs of inadequate care.
- Find local providers: doctors, dentists, counselors, churches that understand dementia.
- Work to build rapport with direct support staff, not just the “bosses”.
- Empathy & patience are important, be sure to acknowledge how hard the work is.
- If it looks or sounds like you aren’t being heard, find someone else.
- It is important to know if you can rely on your loved one’s reporting. If not, find someone you can trust to confirm before making assumptions about care or lack of care.
- If issues are not resolved, contact the Long-Term Care Ombudsman’s Office; every state has one.

Resources

- The Aging and Disability Resource Center or Area Agency on Aging in the community/county/region where the person with dementia lives.
- **Caregiven** is an app you can use to coordinate care between family members.

Communication Guidance

Making It His Idea

I've learned not to say "no" to an idea. I say OK and then offer the best option available. Sometimes the option becomes his own idea and that's really fabulous. For example, my dad wanted to give away my mom's car (it was no longer needed) and said he was going to look in the yellow pages. I said OK. Then I called his church, they would gladly find a family who could use it. I suggested he call the church. The next day he said he was going to call the church!

– **Maureen, Anchorage-based long-distance family caregiver**



Keep it Simple

- Speak slowly and clearly using short simple sentences and familiar words.
- Avoid certain types of questions whenever possible, such as quizzing the person on names of family members. Avoid asking "do you remember...?" Not knowing the answer embarrasses the person, which only reminds them that they don't remember.
- Use direct statements to initiate action, such as "It's time to take a bath," or "Let's get dressed now." Avoid asking if they want to take a bath or shower.

Communicate with more than just words

- Use a normal tone of voice and a calm manner.
- Stand in front or in the direct line of vision of the person. Be sure you are connected with them before you do anything else. Touching an arm or shoulder gently can be helpful to get or keep attention.
- Use gestures and visual cues or aids to get your message across. Try using more than one of the senses to communicate, such as touching as well as talking.

Follow their lead

- Meet the person in the time/era they are in. Unless there is a safety concern, there is no need to keep reorienting the individual to your reality. It may only frustrate them.
- Understand the person with dementia may say one word and mean another. Try to clarify your guess with the person before assuming the correct meaning.
- Communicate with the person as much as possible; however, a constant stream of conversation is neither helpful nor necessary.
- Do not assume the person can understand and act on messages, either written or verbal. Just because they can repeat your words, does not mean they understand.

For additional information, Teepa Snow and the Positive Approach to Care offers many tools for caregivers: teepasnow.com/resources/for-families-and-friends

Another good resource

- **Dementia Careblazers:** www.careblazers.com

Financial Information

LONG-TERM CARE FUNDING

Comprehensive Planning

Limited Asset

Less than \$500K

▼ Considering All Spending Thru Medicaid Lens

Your assets indicate that if you need a nursing home level of care, you will likely access the **Medicaid** system.

Moderate Assets

More than \$500K,
Less than \$3.4M

▼ Considering All Spending Thru Medicaid Lens

Continue with your financial plans. Confirm with your lawyer that your legal documents and wills are in order. **Medicaid could be needed.**

High Assets

More than \$3M

▼ Prepare "Self Funded" Plan

Your assets preclude you from Medicaid assistance. Start a SELF FUNDED PLAN with a Financial Planner. Meet with your lawyer to prepare the legal documents and wills to ensure your wants and needs are met. **Medicaid should not be needed.**

Regardless of your assets, if you are facing a diagnosis that could lead to long-term care, you should:

- 1 Have a family meeting to establish your core values and plan.
- 2 Get familiar with local resources and peer groups available to you.
- 3 Breathe, you are not alone.



Medicaid 5-Year Look-Back Period

The federal government has established a “**look-back period**” for all individuals applying for Medicaid. This is a set period of time prior to the individual’s application during which the Medicaid administering agency reviews all the financial transactions that the applicant has made.

Medicaid Spend Down Planning

For a person to be eligible for nursing home level of care from Medicaid, they must have limited income and assets.

PENALTY: A Medicaid applicant is penalized if assets (money, homes, cars, artwork, etc.) were gifted, transferred, given away, or sold for less than the fair market value within this period. Assets can be spent down on a specific list of things.

Penalties come in the form of a period of time that the applicant is made ineligible for Medicaid. *This means they will not be able to receive care services paid for by Medicaid for a certain number of months. Sometimes this can be used to your advantage.*

SPOUSE: Please note, asset transfers by the applicant’s spouse can also affect the applicant and can result in a Medicaid penalty period for the applicant.

CAREGIVERS: Even payments to a caregiver can be found in violation of the *look-back* period if done informally, meaning no written and legally binding agreement has been made.

The penalty period begins on the date that one becomes eligible for Medicaid, not the date that the transfer or gift resulting in penalization was made.

For example, if you transferred your home to your child on August 5, 2016, but didn’t become eligible for Medicaid until March 16, 2018, your period of ineligibility will begin on March 16, 2018.

It’s important to note, if a gift or transfer was made prior to the look-back period, an individual will not receive a penalty.

This excerpt from a long-term care financial planning workbook is meant as a guide to help you think about and organize your resources. It is not meant to substitute for financial, legal, tax or medical advice from a professional. Information prepared by Marietta Hall CFP® marietta@apcm.net.

Technology

For people living with dementia, technology can offer ways to increase independence and support safety. Technology encompasses a range of adaptations and devices, from low-tech options such as modified utensils to electronic devices such as smart speakers, wearables, and apps that include reminders and schedules.

Many people with dementia find that introducing and using technology as early as possible helps them adapt and use devices long term. Technology can also assist caregivers with organizing support and keeping track of documents and medical appointments. It is best to meet with a professional assistive technology specialist to determine the features that best meet individual needs.

Assistive Technology of Alaska (ATLA) is a statewide, comprehensive resource center. ATLA has several programs in place to assist Alaskans in obtaining solutions and services to increase their quality of life. They assist people with dementia and their caregivers in determining the most appropriate technology solutions.



www.atlaak.org

atla@atlaak.org

907-563-2599

NOTE: *There are many technology options available and more coming all the time. Examples referred to in this guide include Caregiven, Dose Health and Zinnia TV. It is important to note that ATLA does not endorse definitive technologies due to the constantly evolving technology as well as considerations regarding cost and availability in Alaska.*

Examples by type of assistance needed

Daily activities for memory

- **Devices that detect motion** – Motion sensors use a sensor and play a pre-recorded voice when there is movement. For example, a message can play as the person walks out of the kitchen to remind them to turn off the stove.
- **Automatic pill dispensers** – Automatic pill dispensers can come with a variety of features, such as pre-filled and lockable. Some dispensers can set off an alarm and only a specific compartment will open so that the person can access the correct pills.
- **Locator devices** – Locator devices are small Bluetooth-enabled accessories that can be attached to an item that is then trackable from a smartphone.

Safety

- **Fall sensors** – Fall sensors are able to register if the person has fallen and send an alert to the caregiver.
- **Door sensors** – Door sensors can alert caregivers when a door is opened.

Social Engagement

- **Communication programs** – Communication systems can range from low to high-tech. A low-tech communication system may be printed, laminated symbols on a page, where as a high-tech system can be a text or symbol-based app on an iPad. Each of these allow the person to communicate wants, needs, feelings, etc. by selecting words or symbols.
- **Smart speaker** – Smart speakers can also be helpful by allowing a caregiver to connect with the person living with dementia remotely. These devices can also provide auditory feedback when asked questions such as the date, time, weather, upcoming events, and more.
- **Digital games, puzzles and apps** – Digital games, puzzles and apps can be useful for entertainment or mental stimulation. For examples, some puzzle apps allow the person to play with another person remotely, so they can be a good way to keep in touch as well as enjoy the game.

Resources

This is a compilation of information referenced in this Resource Guide. This is not a comprehensive list.

ALASKA-SPECIFIC

General

Aging and Disability Resource Centers:

1-855-565-2017, dhss.alaska.gov/dsds/Pages/adrc/default.aspx

Alzheimer's Resource of Alaska:

907-561-3313/1-800-478-1080, www.alzalaska.org

Office of the Long-Term Care Ombudsman:

(907) 334-4480 or 1-800-730-6393,
email: akoltco@alaska.gov, akoltco.org

Planning Documents or Information

Alaska Advanced Directive: www.caringinfo.org/wp-content/uploads/Alaska.pdf

Alaska Legal Services: 1-888-478-2572,
www.alsc-law.org

Alaska Power of Attorney: www.courts.alaska.gov/shc/family/docs/poa-booklet.pdf

Disability Law Center of Alaska: 1-800-478-1234
or email: akpa@dlcak.org, www.dlcak.org

Financial Planning for Long-Term Care Workbook
by Marietta Hall: www.apcm.net,
email: marietta@apcm.net

POLST (Physician Orders for Life Sustaining Treatment): www.akpolst.org

Caregiving

AARP AK Caregiving guide: www.aarp.org/AKCaregiverResources

Assistive Technology of Alaska – provides free consultations and resources: 907-563-2599 or www.atlaak.org

Mind Aerobics: www.alzalaska.org/mind-aerobics

The ABC's of Choosing a Long-Term Care Facility: akoltco.org/helpful-resources

Well Haven Occupational Therapy specializes in dementia and provides services statewide via telehealth: www.well-haven.com

Veterans

Alaska Office of Veteran's Affairs: email: alaska.veterans@alaska.gov, 888-248-3682 (Toll Free) or 907-334-0874, veterans.alaska.gov/home

AK VA guide: veterans.alaska.gov/media/2062/state-veterans-benefits-booklet-2020-optimized.pdf

VA Caregiver Support Program: 907-375-2606

NATIONAL

General

AARP National Caregiver Resource Line:

1-877-333-5885 (English), 1-888-971-2013 (Spanish)

Alzheimer's Association: www.alz.org/help-support

Dementia Careblazers: www.careblazers.com

Caregiver Support

Teepa Snow/Positive Approach to Care:

teepasnow.com/resources

ALZConnected online community:

www.alzconnected.org

Conversation Starter Kit for Families of Loved Ones of People with Alzheimer's Disease or other Forms of Dementia: theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf

Alzheimer's Association's online "Caregiver Center" has helpful tips on daily care such as activities, providing personal care and managing incontinence: www.alz.org/help-support/caregiving

Key questions to ask when thinking about moving someone into your home: www.aarp.org/caregiving/home-care/info-2021/caregiving-questions.html?intcmp=AE-CAR-CAH-BB

Health-Related

Managing medications: www.nia.nih.gov/health/managing-medicines-person-alzheimers

Living Well with MCI or Early Dementia provides wellness steps, discussion guides and action

plans: www.alz.org/media/mnnd/documents/18_alz_living_well_booklet.pdf

Living with Alzheimer's Taking Action Workbook: www.alz.org/getmedia/da9e2ce1-d73c-437a-be7c-d5761afd06e9/taking-action-workbook

Safety

Home Safety Checklist: www.nia.nih.gov/health/home-safety-and-alzheimers-disease

AARP's HomeFit Guide: www.aarp.org/livable-communities/housing/info-2020/homefit-guide.html

Other

At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia and Driving: s0.hfdstatic.com/sites/the_hartford/files/at-the-crossroads-2012.pdf

Peer Advocacy/Support: dementiaminds.org

A Financial workbook for Family Caregivers (Available in English, Spanish, Chinese and for Veterans): www.aarp.org/content/dam/aarp/secure/caregiving/financial-workbooks/aarp-caregiving-financial-workbook-fillable.pdf?intcmp=AE-CAR-LEG-R3-C1

Caregiven - an app that offers a centralized place to store medical information, team member contacts and critical documents: www.caregiven.co

Wish of a Lifetime (an AARP partner) grants wishes to seniors. wishofalifetime.org



Trust
Alaska Mental Health
Trust Authority

Caregiver Resource Guide