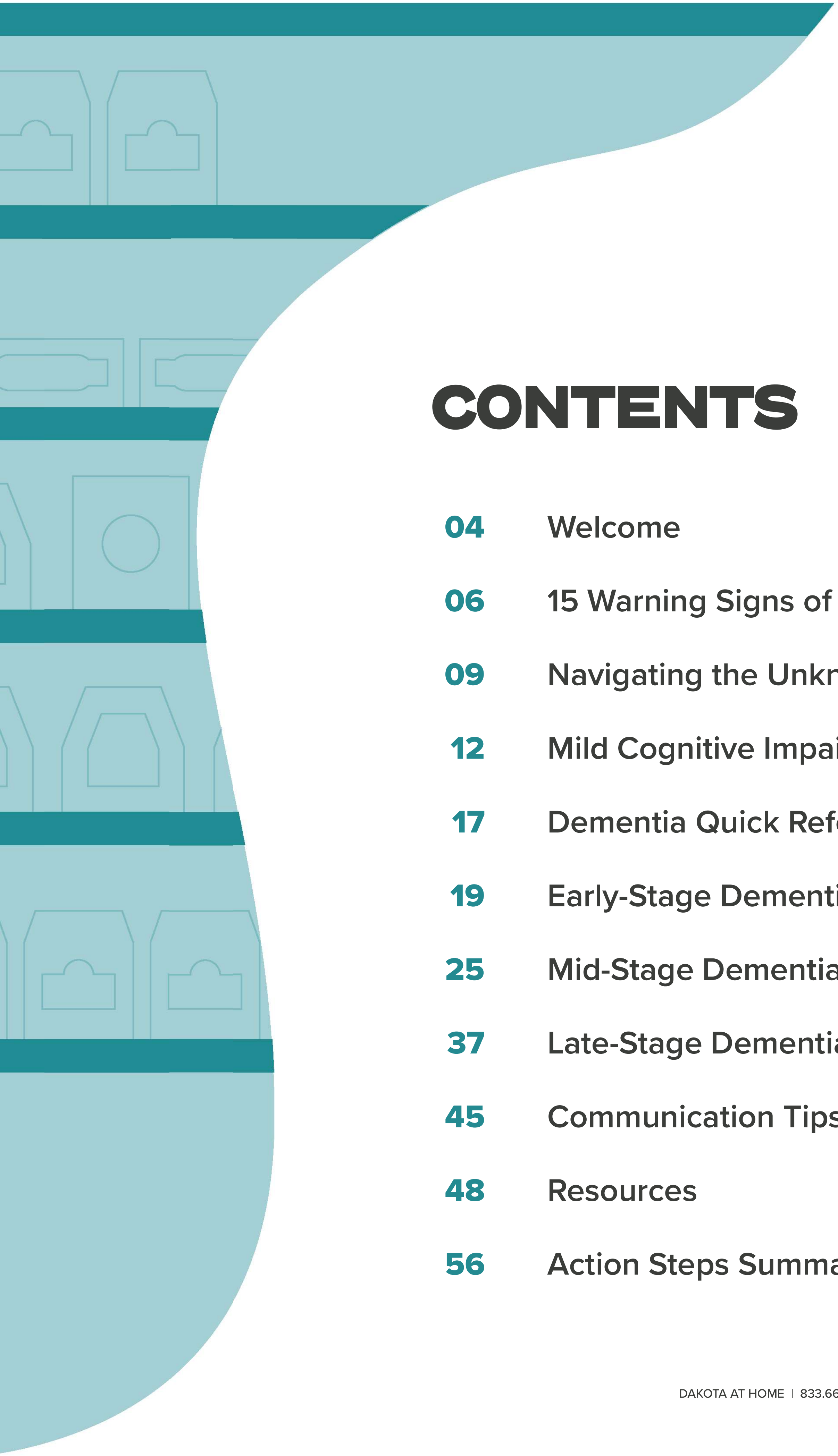
A GUIDE FOR NAVIGATING DEMENTIA

FOR FAMILIES AND CARE PARTNERS

LTSS
LONG TERM SERVICES & SUPPORTS
+
South Dakota DHS



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SOUTH DAKOTA'S GUIDE TO

DEMENTIA SUPPORT

Living with memory loss or dementia is a journey, that can span many years, often with unexpected twists and turns along the way. It's important to remember that this journey isn't the same for everyone and the path is not linear. Each person with Alzheimer's or another form of dementia progresses differently and in their own time. As a family member, caregiver, or companion, you don't have to go through this alone. There is always hope, along with helpful tools and information to guide and support you.

Designed to give you a clearer view of what's to come, this guide includes helpful tips and guidance on important decisions you may face.

IS SOMEONE SHOWING SIGNS OF MEMORY LOSS?

While some changes in thinking and memory can be a normal part of aging, symptoms like confusion, memory loss, and unusual behaviors may be signs of dementia. If you're noticing memory loss or feeling concerned about changes that are starting to affect someone's daily life, it's important to check in with a health care professional.

Early detection and diagnosis is essential. Identifying and addressing memory loss early offers many benefits, including:

- **Finding the underlying cause.** Memory loss and confusion can result from various conditions, some of which are treatable or even reversible. For example, conditions such as sleep apnea, thyroid problems, or vitamin deficiencies may cause reversible dementia symptoms.
- **Getting an early diagnosis.** Understanding a dementia diagnosis can help you and the person living with dementia prepare for the future with greater confidence. Whether the concern is dementia or another condition, seeking a diagnosis helps ensure appropriate care is provided.
- **Improved clinical care.** Health care professionals can provide better treatment for all medical conditions once they have a clear understanding of what's happening through a diagnosis.
- **Better preparation for the future**. Having a clear diagnosis simplifies planning and makes it easier to move forward with the necessary caregiving and support.
- **Enhanced safety.** Recognizing cognitive impairment early can help prevent accidents, wandering, or financial exploitation.
- **Manage and slow progression.** Early intervention can help manage symptoms and slow progression, especially with emerging therapies.
- **Support for family caregivers.** Early diagnosis connects families to resources, support groups, and services sooner.

15 WARNING SIGNS OF DEMENTIA

Short-term memory loss

Word loss

Difficulty multitasking

New sleep behaviors

Personality Changes

Worsening sense of direction

Repeating questions or statements

Depression

Confusion about time and place

Financial missteps

Changes in judgement

Difficulty with visual or perceptual tasks

Misusing items

Hallucinations or delusions

Misplacing things

SOURCE: aarp.org/health/conditions-treatments/dementia-warning-signs/

ALZHEIMER'S & DEMENTIA—WHAT'S THE DIFFERENCE?

Dementia is a general term used to describe a loss of cognitive abilities such as memory, thinking, or reasoning, that is significant enough to interfere with a person's daily life.

It is important to know that dementia is not a single specific disease, **nor is it a normal part of aging.** Instead it refers to a group of symptoms caused by damage to the brain due to illness or injury.

Alzheimer's disease is the most common cause of dementia, but it's not the only one. Other types include vascular dementia, Lewy body dementia, frontotemporal dementia, and more.

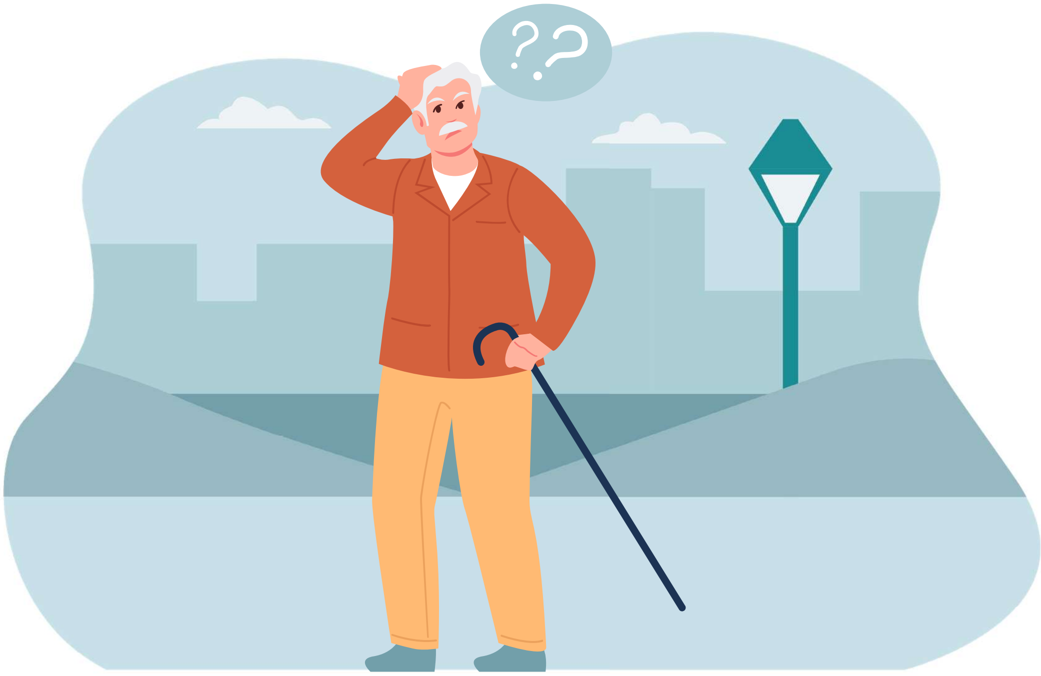
Recognizing that dementia is the result of physical changes in the brain can help to approach care with greater understanding and patience.

TERMINOLOGY

Throughout this guide, we use several terms to describe the people involved in the dementia care journey. Understanding these terms can help clarify roles and expectations:

- **Person Living with Dementia (PLWD):** Refers to the individual experiencing memory loss or living with dementia.
- **Care Partner or Family Caregiver:** The primary individual(s) providing the majority of day-to-day support, supervision, or hands-on care. Care partners play a central role in helping manage health, safety, and quality of life.
- **Other Friends and Family:** Refers to the extended support networks who may not be involved in daily care but can provide emotional support, occasional help, or respite for the primary caregiver.

Note: *While each person's situation is unique, this guide encourages a team-based approach to caregiving whenever possible.*



NAVIGATING THE

UNKNOWN

WHAT TO EXPECT

Once you begin to notice changes in someone's thinking or memory, you might find yourself wondering, "Is this really affecting their daily life?" In the early stages, the signs can be subtle and easy to dismiss. You may observe that the PLWD:

- Struggles to complete tasks that require multiple steps
- Has difficulty solving problems or making decisions independently
- Forgets recent events or conversations
- Takes longer to complete mentally demanding tasks, such as using a computer or managing finances

The person living with dementia may be aware something is changing, but they might feel uncomfortable bringing it up or discussing it. At the same time, other friends and family may not notice these early signs, or any changes in behavior.

WHAT YOU CAN DO

Understand What's Normal and What's Not
Learn about typical changes that come with aging versus signs that may indicate a more serious issue and may warrant getting a check-up. The Alzheimer's Association's *"15 Warning Signs of Dementia"* is a great place to start (pages 6 & 7).

Keep Track of Changes
Start a journal, a note on your phone, or any place that is easy to access and update regularly where you can record specific concerns you've noticed regarding thinking or memory. This can be helpful when speaking with the person living with dementia (PLWD) or health care providers.

Have a Gentle Conversation
If they haven't brought up the changes, find a calm, respectful time to talk about what you're seeing. It's best to approach the conversation with empathy and concern.

Schedule a Medical Check-up
Schedule a full medical check-up for the individual showing symptoms. As mentioned, the memory loss and confusion may have an underlying cause—like sleep apnea, thyroid problems, or vitamin deficiencies—and may be reversible. Even if it can't be reversed, it's best to know what you're dealing with when it comes to memory loss symptoms.

If the individual showing symptoms is on Medicare, ask their primary health care professional to schedule a Medicare Annual Wellness visit. This consists of twelve components, including, but not limited to, a cognitive assessment, activities of daily living assessment, hearing screening, advanced care planning, past and recent medical history, and more. If their health care professional notices anything that requires further testing, they can help you set up a specialist follow-up visit.

Choose a Trusted Provider
If you're uncomfortable talking to the current health care professional for the PLWD, you can seek a different one. Most primary care professionals can diagnose dementia, but specialists like neurologists, geriatricians, or

memory clinics are also viable options and could be considered for a second opinion. If you're looking for a provider, you can contact the Alzheimer's Association's 24/7 Helpline to help identify options in your area.

Get Help if They're Hesitant to Schedule or Follow Through with a Medical Check-up

If the PLWD doesn't want to get a medical check-up, enlist the help of a trusted family member or friend who could help provide encouragement. At times, hearing a different or another voice of concern prompts action.

Explore Possible Hearing Loss

If you suspect the PLWD is having trouble hearing, get it checked and addressed. Hearing loss can negatively impact a person with memory loss or confusion, which leads to more misunderstandings and social isolation.

Support and Encourage Healthy Lifestyle Choices

Encourage and take advantage of opportunities for both you and the PLWD to:

- Stay active in social groups, arts, and other hobbies
- Eat a balanced, nutritious, healthy diet
- Stay or be physically active
- Get a good night's rest of 6-8 hours of uninterrupted sleep

Start Planning Ahead

Prioritize beginning or completing any legal, financial, and medical advance care planning (including essential planning documents like power of attorney, health care directives, wills, etc.). 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 these changes may or may not end up being dementia, it is critical to complete this planning while they are still able to participate fully in these decisions.

MILD COGNITIVE IMPAIRMENT

Mild Cognitive Impairment (MCI) refers to a noticeable and measurable decline in cognitive abilities such as memory and thinking, that goes beyond normal aging. However, MCI does not significantly interfere with daily life or independence, and is not considered dementia.

While individuals with MCI have a higher risk of developing dementia later on, this is not certain. Some people remain stable or even improve over time, depending on the underlying cause.

WHAT TO EXPECT

An individual with MCI may have symptoms that include:

- Forgetting things more often
- Missing appointments or social events
- Losing their train of thought, or not following the plot of a book or movie
- Trouble following a conversation
- Trouble with language or finding the right word
- Finding it hard to make decisions, finish a task, or follow instructions
- Trouble finding their way around places they know well
- Poor judgment
- Changes that are noticed by family and/or friends

People with MCI may also experience:

- Depression
- Anxiety
- Short temper and/or aggression
- A lack of interest
- Paranoia

As a care partner, it’s completely normal to experience a wide range of emotions and reactions. You may:

- Feel grief, stress, or uncertainty
- Experience frustration or irritation with the person living with dementia’s (PLWD) differing abilities
- Feel compassion and protectiveness as you see how these changes are affecting them
- Notice that friends, family members, or co-workers don’t see the changes or understand your concerns, which can feel isolating

These feelings can be confusing and may even conflict with each other. Caring for someone with cognitive changes is complex and your emotional responses are valid.

WHAT YOU CAN DO

- Ask the person living with dementia (PLWD) if you can attend their medical appointments so you can share your observations and offer support to them during the visit.
- Consult reliable resources about Mild Cognitive Impairment (MCI) while you are seeking medical care. This will help you understand the condition and stay aware of whether the symptoms are progressing.
- Consider asking the health care provider for an order for Speech or Occupational Therapy as these therapies specialize in treating cognitive impairment and help the PLWD and families learn how to fight against brain changes.
- Talk to your own health care provider about the care you are giving the PLWD so they can be aware of your own potential health-related risks.
- Remind yourself that the PLWD isn't forgetting or struggling on purpose. They're doing the best they can with the abilities they have. This isn't about trying harder.
- Give yourself credit for providing caregiving and showing up. Give yourself some grace and remind yourself you're doing the best you can.
- Turn everyday tasks like paying bills and shopping into activities you can do together so they can have successes while giving you both a sense of teamwork.
- As mentioned previously:
    - Keep track of changes to share at medical appointments—such as new or different behaviors, medication changes or effects, changing abilities in taking care of finances or appointments
    - Utilize Medicare's annual wellness visits if the PLWD is on Medicare
    - Encourage a medical check-up
    - Support and encourage healthy lifestyle choices

TO HELP THE PERSON LIVING WITH DEMENTIA

- Help them in managing any medical conditions—like high blood pressure or diabetes—as needed. This may include helping them to manage medications. You can find tips at the URLs below:

  doh.sd.gov/topics/healthy-living | **doh.sd.gov/topics/diseases**

- Support and encourage healthy lifestyle choices such as regular exercise, a healthy diet, and participating in social activities with others.
- Encourage the use of long-time skills, like playing an instrument, singing, typing, crafts, or enjoying other favorite hobbies.
- Contact the Alzheimer's Association for information and guidance on living well with this disease and planning for the future.

REDUCING DEMENTIA RISK FOR YOU & OTHERS

While dementia can't always be fully prevented, making smart lifestyle choices may help reduce risk or delay symptoms. Up to 45% of dementia cases may be preventable through positive lifestyle changes. Healthy habits like these can be beneficial to anyone, whether they're at risk or not.

Risk Factors to Address

- High blood pressure
- Diabetes
- Smoking or excess alcohol
- Depression
- Physical inactivity
- Social isolation
- Hearing or vision loss

Healthy Habits to Embrace

- Exercise regularly
- Follow a brain healthy diet such as the DASH, MIND, or Mediterranean diet
- Stay socially active
- Get enough sleep
- Manage chronic conditions
- Continue learning and challenging your brain
- Wear hearing aids or glasses if needed

Educate younger family members that brain health starts early and encourage early adoptions of healthy habits. Education, creativity, good sleep, physical fitness, sensory care, and positive social connections matter for everyone while building lifelong cognitive resilience.

Visit the South Dakota Department of Health website on Healthy Living:
doh.sd.gov/topics/healthy-living/

QUICK REFERENCE

EARLY–STAGE DEMENTIA

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

MID–STAGE DEMENTIA

- Increasing needs for care and supervision
- More trouble with memory like address or personal history
- Problems organizing/planning, following instructions and solving problems
- Not recognizing familiar people
- Difficulties with reading, language and communication
- 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 DEMENTIA

- Dependent for personal care activities
- Not recognizing you or others by name (this does not mean they don’t know or feel who you are)
- Changes in physical abilities including ability to walk, sit and eventually swallow
- Frequently or totally incontinent.
- Rigidity, immobility, jerks or seizures
- Increasing difficulty communicating—may use “word salad” (mixed up words) or be speechless
  Non-verbal communication may work best
- May feel deep emotions and may scream, moan, or flail
- Vulnerable to infections, especially pneumonia

EARLY-STAGE
DEMENTIA

WHAT TO EXPECT

During this stage the person living with dementia (PLWD) is starting to have trouble with daily tasks or routines, they may also experience some or all of the following:

- Confusion with time, the sequencing of events, or getting lost even in familiar places
- Forget or have difficulty recalling names of familiar people and/or objects
- Decreased performance in work or withdrawing from social situations that previously brought joy
- Trouble multi-tasking, planning, or following multiple step instructions
- Take more time to process information
- Write reminders and lose them
- Increased preferences for familiar people, places, and/or objects
- Mild mood changes
- Feel and display excessive sorrow, suspicion, anger, or frustration
- Loss of interest in previously enjoyed activities
- Show increasing indifference to normal courtesies or social norms
- Have difficulty driving safely
- Behaving out of character
- Misplacing items and being unable to retrace steps
- Trouble judging distances
- Difficulty reading
- Unable to find appropriate words, follow conversation, or write legibly

You might notice that the PLWD has difficulty remembering recent events, while they will likely remember stories from long ago. They may also remember how to do activities that they are familiar with (like playing an instrument or a lifelong hobby), and be able to focus more on the present moment, enjoy a sense of humor, and a growing ability to be creative.

AS A CARE PARTNER

- You may feel mixed emotions of optimism and an early sense of loss and grief
- You may notice a need to provide more or repeated reminders and supervision
- You may want to ask for help around the home with everyday tasks such as housekeeping, errands, laundry, or yard care
- You may be inspired by how the PLWD continues to adapt and grow, even in the midst of challenges
- You may start building a support team (a network of caring friends, relatives, neighbors, community members, etc.) who will be able to help you when the need arises

WHAT YOU CAN DO

Practice Self-care

- Embrace the good days and stay prepared for the stormy ones
- Make your life a guilt-free zone
- Cherish moments of joy
- Acknowledge your feelings and seek emotional support
- Ensure your wellbeing by setting boundaries and accepting help

Choose a Trusted Provider

- Be an advocate for the right diagnosis and best health care. If you're uncomfortable or not happy with current care, find a health care professional that will work with you and the person living with dementia together.
- If you're looking for a provider, you can contact the Alzheimer's Association's 24/7 Helpline to help identify options in your area.
- Consider enrolling them in a clinical trial or research study on dementia if they're comfortable doing so. The person living with dementia (PLWD) may be able to advance the understanding of dementia and help in the effort to develop new treatments. Contact your physician and/or the Alzheimer's Association to learn more.
- Go along on medical appointments if the PLWD agrees. If they do not agree, try getting a hold of the medical professional (through a patient portal, send a letter or note, or hand a note to a staff person on the day of the appointment) ahead of appointments to share concerns and observations.

Educate Yourself

Learn all you can about the disease and tips for communicating with the person living with dementia in a supportive manner. See Communication Tips (pg 45).

Prioritize Safety

Put safety measures in place before they're needed in relation to falls, wandering, medication usage, harmful cleaning products, guns, power tools, etc. You can find safety information in the Resource Section (pg 48).

Have a Plan

- Complete legal, financial, and medical advanced care planning directives including how the PLWD wants to live at the end of their life and document the information.
- Consider ways to protect yourself and the PLWD from financial missteps and exploitation such as removing their credit cards (or lower credit limits) and other key wallet documents.
- Develop a backup plan that can be used if something happens to you and someone else needs to step in as the primary caregiver.
- Review information regarding dementia and driving and develop a plan. Consider discussing and having them sign a driving contract (a pre-arranged, non-legal agreement where the individual, while still in the early stages of dementia, gives a trusted caretaker(s) permission to intervene and stop their driving when it becomes unsafe due to cognitive decline).

Explore & Monitor

- Create and stick to simple routines.
- Monitor medications and ensure they are taken properly.
- Get hearing checked regularly and ensure hearing aids are in good condition.
- Get eyes checked regularly and ensure glasses are in good condition and used as instructed.

Encourage Independence

- Resist the urge to complete activities or tasks that the PLWD can do for themselves. Allow additional time, and the occasional error.
- Look for ways to modify their favorite activities rather than give them up. Assist them with their activities of interest.

Practice Understanding

When you see behaviors that seem “out of character,” do NOT take these personally. Help family and friends understand how to communicate and interact. If needed, you can share what they like to do, topics of conversation, and the need to avoid correcting and arguing.

Support and Encourage Healthy Opportunities

- Stay active in social groups, arts, and other hobbies
- Eat a balanced, nutritious, healthy diet
- Stay or start being physically active
- Get enough and good sleep every night
- Find support for you and the person living with dementia (PLWD) through support groups (in-person and/or online) and talk with others who have had similar situations
- Encourage the PLWD to attend early stage support groups and seek out dementia-friendly recreation activities such as memory cafés where care partners and their companion with dementia socialize with others (both in-person and online)

SERVICES TO CONSIDER

As a care partner (caregiver), it's important to begin exploring resources early to ensure the person living with dementia can live with dignity, safety, and engagement. Some services to consider are:

- Educational workshops and seminars
- 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"
- Explore information, resources, and other services in South Dakota at **dhs.sd.gov**

MID-STAGE DEMENTIA

WHAT TO EXPECT

During this stage, often lasting 2-4 years, confusion becomes more apparent and daily-life independence diminishes. The person living with dementia (PLWD) may have increasing needs for care, support, and supervision. They may experience some or all of the following:

- Significant memory loss such as recalling their own address or personal history, or familiar names
- Reduced ability with organizing, planning, following multi-step instructions, and solving problems
- Forgetting how to initiate routine tasks or how to complete them, including health and hygiene care
- Poor word-finding, speech interruptions, and reduced ability to understand conversations
- Resistance to bathing, dressing, or other personal care and may have episodes of incontinence with bladder and/or bowels
- Abilities that vary from one day to the next
- Complaints of neglect or blaming others when things go wrong
- Trouble sleeping or a disordered sleep-wake cycle
- Late-day restlessness and confusion also referred to as "Sundowning"
- Apathy, passivity, withdrawal, irritability, and agitation
- Repetitive questions
- Irritability, aggressive talk and actions
- Clinging (following you around or shadowing)
- Wandering
- Delusions and paranoia (false beliefs) and/or hallucinations (seeing/hearing things that aren't there)
- More issues with balance (increasing the risk of falls)
- Not being able to contribute to family life in traditional ways
- Sensitivity to caregivers' moods and behaviors
- A lack in judgment

At the same time, the PLWD 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 express creativity.

For the care partner this stage typically requires more hands-on involvement, emotional resilience, and adaptability as the person with dementia loses more independence.

AS A CARE PARTNER

- It's normal to feel tired, stressed, or even lonely and overwhelmed at times
- Emotions such as grief, sadness, guilt, or frustration may come and go, but they do not define your strength or commitment
- Reflecting on your own limits shows courage and self-awareness, not weakness
- Friends and family often want to help. Accepting their support can lighten your load and remind you that you are not alone
- Amid the challenges, there can also be moments of joy, connection, and deep meaning in the care you provide

WHAT YOU CAN DO

Practice Self-care

- Embrace the good days and stay prepared for the challenging ones
- Make your life a guilt-free zone (forgive yourself when rest or support is needed)
- Cherish moments of joy
- Acknowledge your feelings and seek emotional support
- Ensure your wellbeing by setting boundaries and accepting help
- Stay active in social groups, arts, and other hobbies
- Eat a balanced, nutritious, healthy diet
- Choose regular movement
- Get enough and good sleep every night
- Find and attend support support groups (in-person and/or online) and talk with others who have had similar situations
- Vent as needed with trusted friends or other caregivers

Contact a Trusted Provider

Call on the support team you identified during the early stage of dementia to secure relief from care tasks (sometimes known as Respite Care).

Routine & Mental Health

- Establish or maintain routines for you and the person living with dementia (PLWD)
- Practice not taking behaviors personally, remember it's the disease and try not to mistake the PLWD's negative actions/reactions as intentional
- Ask for help with taking care of the home or providing care:
    - Housekeeping
    - Errands
    - Yard Care
    - Handy Person
    - In-Home Assistance for the PLWD
- If you get unwanted advice or criticisms, pause and consider that others may be offering support in their own way. Try to explore how they might be helpful. Most importantly, remind yourself that you are doing the best you can.

Prioritize Safety

Ensure safety by addressing key risks: reduce fall hazards, prevent wandering, secure medications, and lock away dangerous items such as chemical cleaners, firearms, and power tools.

Explore & Monitor

- If the PLWD is still driving, consider involving their health care provider to help initiate a conversation about retiring from driving.
- Explore available services and supports that support maintaining current living arrangements safely, such as in-home care or adult day services.
- Begin researching and reviewing long term care options such as assisted living homes, nursing homes, community living homes, or other residential care settings in the event they are needed down the road. Review their costs, availability, and take tours so you're prepared if you need to make a quick decision.

TO HELP THE PERSON LIVING WITH DEMENTIA

- Encourage family and close friends to learn dementia-specific communication tips and techniques—and to help provide activities the PLWD still enjoys. Refer them to the Alzheimer's Association website or 24/7 toll-free helpline: 1.800.272.3900.
- Approach with kindness, understanding, and acceptance.
- Channel their energy—go for regular walks together, encourage them to help with chores like vacuuming, sweeping, folding laundry, and gardening.
- Simplify tasks and activities, break them into smaller steps—allow more time for the PLWD to accomplish them.
- Reminisce—look at old photo albums, a memory book or old videos.
- Ensure ongoing medical care, track changes (sudden and gradual). If you notice any sudden changes in behavior, call the PLWD's health care professional as this can be a sign of infection or other medical issue.

- If advance directives have not been completed, talk to the person living with dementia's (PLWD) doctor about completing the Portable Orders for Life-Sustaining Treatment (POLST) form, Do Not Resuscitate (DNR) form, Medical Orders for Scope of Treatment (MOST) form, and other pertinent medical directive forms.
- Ask for a referral to a Physical or Occupational Therapist for a home safety evaluation.
- In South Dakota, caregivers have free access to Trualta for online training and resources to help caregivers build skills and confidence to provide care for people at home, including self care techniques, reducing stress and burnout, and virtual support groups. Learn more at **caregivers.trualta.com.**
- Attend education workshops or conferences for caregivers.
- Explore assistive technology to help with a variety of tasks—reminders, cameras, chimes to alert if an exterior door opens, etc.
- Respite care can give you temporary relief from caregiving. Call Dakota at Home to learn more about programs that may be available to you.
- Adult day services offer people 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.
- Engage in counseling to manage grief, depression or anger, and get emotional support. These feelings are normal and valid.
- All suggestions don't work the same for everyone so don't get discouraged. This is not your failure. Try something else to see what works best for the PLWD.

Explore information, resources and services in South Dakota at **dhs.sd.gov** or call Dakota at Home at 1.833.663.9673.

ADDING ROUTINE & COMFORT

Daily routines can offer the PLWD a greater sense of security and help reduce anxiety or confusion. Including them in simple, familiar tasks such as setting the table or folding laundry can help provide a sense of purpose and connection to everyday life.

Daily Routines to Consider

Morning
Start the day with gentle personal care (washing face and hands, brushing teeth), get dressed together, prepare and enjoy breakfast, read aloud or look at photos and take a walk.

Afternoon
Share lunch, engage in light chores such as watering plants or folding towels, visit with a friend, enjoy quiet time and rest.

Evening
Prepare dinner together, enjoy music or favorite shows, look through magazines, start a calming bedtime routine.

Creating a consistent flow to the day helps support cognitive function, encourages participation, and promotes emotional well-being for both you and the person living with dementia.

MAKE AN ACTIVITY BAG

Prepare an “activity bag” with simple items that bring joy and engagement—like postcards, pictures of family/friends, snacks, magazines, fabric swatches, fidget blankets, puzzles, aprons, weighted blankets, or soft Nerf balls. Have this on hand to keep the person living with dementia stimulated and busy.

RESPONDING TO COMMON CHALLENGES

As dementia progresses, changes in actions and responses may occur that can be confusing or distressing for both the person living with dementia (PLWD) and their care partner. These are not deliberate behaviors, but rather expressions of the disease and not intentional actions. Being prepared can help you respond with patience, compassion, and confidence.

Repetitive Actions
People living with dementia may repeat questions, actions, or phrases due to memory loss, anxiety, or a need for comfort and structure. Repetition is often a way to seek reassurance, support, or cope with disorientation.

> *Offer reassurance and consistency. Respond calmly and as often as needed with phrases such as, "You're safe. I'm here."*

> *Redirect to meaningful activity. Offer or engage the person in a simple, familiar task such as folding laundry, sorting objects, or organizing items to channel energy.*

Suspicion or Paranoia
Delusions and mistrust can arise as memory and reasoning decline. A person living with dementia might believe someone is stealing from them, have suspicions of infidelity towards their partner, or think that others are plotting against them. These perceptions appear and feel real to the individual and are often due to confusion or fear.

> *Avoid confrontation, correction, or arguing. Acknowledge their distress and offer calm, simple, reassuring responses such as: "That sounds upsetting. Let's see what we can do together."*

> *Use distraction. Redirecting attention with a favorite activity, walk, or snack can help to shift focus away from distressing thoughts.*

> *Maintain routine and minimize confusion. Consistency in daily structure, labeling drawers/doors, and limiting unnecessary stimuli can help reduce anxiety-driven paranoia.*

Aggression

Aggression in mid-stage dementia may be verbal (e.g. yelling, threats) or physical (e.g., hitting, pushing). It is often a form of communication signaling discomfort, fear, or unmet needs the individual is unable to communicate.

> *Identify and address potential triggers. Common causes include pain, hunger, fatigue, overstimulation, unfamiliar environments, or a combination of these factors. Assess the situation to help de-escalate the situation.*

> *Remain calm and non-confrontational. Speak in a soothing, low, reassuring tone.*

> *Avoid sudden movements or direct eye contact if it seems to increase the agitation.*

> *Give safe, personal space and allow time for the person to calm down. Avoid pushing interaction during the high distress moment as it may increase the agitation.*

> *Offer comfort and validation saying phrases such as, “I can see you’re upset. I want to help.” This can help the person feel heard without arguing or trying to correct them.*

Hallucinations or Delusions

A person living with dementia (PLWD) may see, hear, or believe things that are not real (e.g., seeing people who aren't there, thinking someone is stealing from them).

> *Acknowledge feelings and perceptions by saying phrases such as "That must be scary. I'm here with you." can be helpful and reassuring.*

> *Use gentle redirection—shifting attention to familiar activity, music, walk, or calming environment elsewhere can reduce fixation on the hallucination or delusion.*

> *Ensure safety and reduce triggers such as poor lighting, unfamiliar surroundings, or mirrored surfaces. Simplifying the environment can be helpful.*

Sundowning

This refers to increased confusion, restlessness, or agitation that often occurs in the late afternoon or early evening. The exact cause is not fully understood, however fatigue, low light, and changes in routine can all be contributing factors.

> *Create a calm evening environment, reduce noise and clutter. Dim lights gradually to help the evening transition.*

> *Plan quiet, comforting activities late in the day such as reading, listening to calming music, offering a hand massage, or other soothing activities may ease anxiety later in the day.*

> *Stick to a routine, keeping meals, medications, and rest times on a consistent schedule can help prevent overstimulation.*

> *Avoid caffeine and larger meals later in the day as they can disrupt sleep and increase agitation.*

Wandering

A person living with dementia (PLWD) may develop a strong urge to walk or move about, often without a clear destination. These situations can become concerning and even dangerous if the person becomes disoriented or leaves the home unnoticed.

> *Secure the environment by keeping exterior doors locked, using door alert systems, storing shoes, clothes, and keys out of sight to reduce the cues to leave.*

> *To help reduce restlessness, offer purposeful movement such as daily walks, light exercise, or tasks that can meet the need for physical activity.*

> *Consider ID and tracking tools such as a medical ID bracelet, enrolling in a GPS tracking program or using a smartwatch (e.g., MedicAlert + Alzheimer's Safe Return®).*

Driving Safety

In mid-stage dementia, changes in memory, decision making, and reaction time make driving unsafe, even if the person still feels and believes they are fully capable of this task.

> *Start the conversation early while the person is still able to participate in planning alternatives such as public transit, ridesharing, caregiver driving, etc.*

> *Be honest and empathetic, express concern for their safety and the safety of others. Focus on helping them maintain their independence in other ways.*

> *Involve a physician if needed to help reinforce the message.*

> *Consider an assessment of driving skills to determine if the individual should still be driving. Locate an assessment location by visiting the South Dakota Department of Public Safety Aging Drivers page.*

> *Consider taking an educational course to review skills and rules of the road.*
>
> **AARP Driver Safety**
> 1-888-OUR-AARP
>
> **AAA RoadWise for Seniors**
> 1-800-222-4545
>
> **South Dakota Safety Council Defensive Driving Courses**
> 1-605-361-7785

LATE-STAGE
DEMENTIA

WHAT TO EXPECT

In the late stage, the person living with dementia (PLWD) will need full-time care and assistance with all aspects of daily living. The disease has significantly affected the brain's ability to manage basic physical and cognitive functions.

They will likely be completely dependent on others for personal care, including bathing, dressing, eating, drinking, using the toilet, and mobility. Many individuals lose the ability to walk, speak clearly, or recognize loved ones. Communications may be limited to facial expressions, gestures, or a few words. Other common changes in this stage may include:

- No longer recognizing you or others by name. This does not mean they have lost the feeling of who you are or the bond you share.
- Talking may become more difficult; sometimes words may get mixed up ("word salad"), or speech may stop altogether. In these moments, nonverbal communication like gentle touch, eye contact, and tone of voice often work best.
- Incontinence may become frequent or constant.
- Physical changes may include trouble walking, sitting, or swallowing. Some people may also develop muscle stiffness, tremors, or involuntary movements.
- Spoken words may fade, but emotional responses remain strong. You may observe expressions such as crying out, moaning, or restless movements, which can signal discomfort.
- Paying close attention to body language, facial expressions, and sounds is key to recognizing discomfort and responding with calm reassurance.
- Vulnerability to infections increases, especially pneumonia, urinary tract infections, skin breakdown, and pressure sores. Preventative care, such as gentle repositioning, good hydration, skin care, and monitoring for subtle signs of infection (like confusion, restlessness, or fever), is very important.

Even in the midst of decline, the PLWD may remain sensitive to the emotions of those around them, take comfort in companionship and respond positively to gentle physical touch or familiar music. Remember and encourage others to slow down, be present, and meet them in the moment.

HELP WITH DAILY CARE

Caring for someone with late-stage dementia involves more than meeting physical needs, it's about creating a calm, respectful, and supportive environment where dignity and comfort are preserved. As abilities decline and the PLWD's needs become more complex, they will require support with many daily activities and your approach matters now more than ever. Helping them maintain dignity while staying safe is essential. When speech fades and recognition dims, they can still feel kindness, sense your tone of voice, and respond to your presence. This section offers practical suggestions to ease everyday care.

General Tips

- Break tasks into small manageable steps such as "Let's put on your socks." Avoid giving multiple instructions at once.
- Use clear calm speech, avoid complex questions and show what you'd like them to do rather than just telling them.
- Offer only two options such as "would you like the blue shirt or red one?" Sometimes offering no choice at all is best such as when the task is essential and/or time sensitive.
- Be patient and flexible, if something is met with resistance, pause and try again later.

Bathing

Bathing can feel invasive and confusing in late-stage dementia; focus on comfort and safety:

- Use soft indirect lighting, warm room, and warm towels.
- Keep bath time short, gentle, and relaxed.
- Avoid harsh or commanding language—if they resist, try again later with a different approach.

Eating

Appetite may decline and swallowing can become more difficult. Creating a supportive mealtime environment is key:

- Keep table settings simple with minimal clutter to reduce confusion.
- Serve one food item at a time, visual processing is generally limited.
- Use contrasting dishware to help with visibility such as a red plate on a white tablecloth.
- Offer favorite foods, even in smaller portions, and watch for signs of swallowing difficulty. You may need to consider thickened liquids or a modified diet if swallowing concerns arise.
- Allow plenty of time to eat, and use calm encouragement.
- Keeping conversation minimal while eating allows the person to focus comfortably on one task at a time.

Toileting

Incontinence is common and out of the person's control. Routine is essential.

- Establish a routine and provide gentle reminders (e.g. 2-3 hours after meals offer a gentle reminder or lead them to the bathroom).
- Keep the bathroom well-lit and marked with a sign or photo, this will make the bathroom easy to locate.
- Consider clothing that is easier to remove, such as pants with an elastic waistband.

Sleeping

Sleep patterns often change in late-stage dementia, and creating a calming environment can help improve rest.

- Create a consistent and calm bedtime routine with quiet activities such as reading, soft music, and a hand massage.
- Reduce screen time and stimulating noise.
- Use a dim nightlight and encourage a familiar sleep space.
- Encourage daytime exposure to natural light and gentle physical activity, which help support sleep-wake cycles.
- Avoid caffeine and large meals later in the afternoon and close to bedtime.

AS A CARE PARTNER

- Grief can be deep and ongoing
- Often called anticipatory grief, awareness that the person living with dementia’s (PLWD) end-of-life is approaching can bring strong emotions. Taking time to prepare emotionally and practically can help you approach this period with presence and a sense of peace.
- Noticing friends and family may also be grieving or struggling. Sharing feelings and supporting one another can help everyone feel less alone.

WHAT YOU CAN DO

- Be kind and gentle with yourself and your loved one. Respect yourself for the love and support you have provided for your loved one and yourself.
- Give yourself permission to feel a range of emotions such as grief, frustration, guilt, sadness, or even relief. These are all normal and valid.
- Allow plenty of time for tasks, quiet time, conversations, and activities—don’t rush.
- Focus on being together in ways that don’t require words such as holding hands, sitting quietly, or listening to music.
- Actively seek palliative care (early in the process) or hospice care as your loved one nears the end of life.
- Ask your loved one’s health care professional (team) to review current medications, especially those that may no longer provide benefit or may cause side effects 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 for dementia caregivers, grief, or anticipatory loss.
- Consider including your closest friends and family in discussions about the end-of-life preferences and plans that have already been made.

Explore late-stage dementia information, resources and services in South Dakota on page 48 of this book.

TO HELP THE PERSON LIVING WITH DEMENTIA

- Keep routines simple and calming. Short periods of activity followed by rest can help maintain comfort and stability.
- Spend time outdoors whenever possible—sit on the porch, feel the breeze, or take a slow walk together.
- Share memories through storytelling, using old photos or videos. Focus on narrating their story rather than testing memory. For example: “Here you are with dad at the lake, what a beautiful day that was.”
- Use music to connect. Favorite songs often remain meaningful, even in the final stages. Sing together or play music they enjoy.
- Engage the senses. Offer fresh-squeezed juice, scented lotions, flowers, familiar foods, gentle lighting, or natural views to create comforting experiences.
- Encourage regular visits from family and friends, even if the person living with dementia cannot speak or walk they still respond to kind words, gentle touch, and hugs.
- Seek support for yourself. Join caregiver, grief, or anticipatory loss support groups to share experiences and find encouragement. See page 48 for resources.
- Include trusted loved ones in end-of-life planning conversations, ensuring everyone understands preferences and plans that have already been made.

SERVICES TO CONSIDER

- In-home care with the help of home health aides, visiting nurses, or professional caregivers trained in dementia care.
- Residential care such as a memory care facility, skilled nursing home or other long-term care community that specializes in advanced dementia.
- Palliative care focuses on relieving symptoms such as pain, anxiety, shortness of breath and improving quality of life at any stage of a serious illness.
- Hospice care offers a holistic approach, including medical care, emotional and spiritual support as well as guidance for the family and is typically used in the final six months of life.
- Support groups may provide connection with others sharing similar experiences, it's a space to share emotions and cope with common challenges.
- Consider counseling or other emotional support for yourself.

Explore in-home care information, resources and services in South Dakota on page 48 of this book.

COMMUNICATION TIPS

Dementia affects how the brain works, which can make it hard for someone to express themselves or understand what others are saying. The person living with dementia (PLWD) might have trouble finding the right words, forget names, or sometimes make up new words. They may also repeat the same question over and over.

As dementia progresses, communication becomes more challenging. Sometimes, what they say might not make much sense, or they might have trouble following what you're saying. These misunderstandings can be stressful and make conversations feel even harder for everyone involved.

Over time, a PWLD may have more difficulty organizing their thoughts, might lose track of what they're saying, or speak less often.

WHAT YOU CAN DO

- **Be present.** Let the person living with dementia (PLWD) know you're listening and trying to understand. Hold the person's hand while you talk. Smile, nod, make appropriate eye contact.
- **Show respect.** Offer them your undivided attention, don't multi-task. Include them in conversations, don't talk about them as if they weren't there.
- **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.
- **Focus on feelings.** Listen for the meaning behind the words. Their tone or body language may provide clues. Respond to the emotions.
- **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.
- **Adjust for hearing loss.** When speaking, directly face the person and be sure your mouth is visible so they can see lip movements. Ensure hearing aids are inserted and working. Get hearing checked regularly.
- **Keep it simple.** Use short sentences. Ask one question or offer one instruction at a time. It usually helps to use "positives" like "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.
- **Use visual cues.** Gestures or other visual cues can help promote better understanding than words alone. Rather than asking if the PLWD needs to use the toilet, walk them to the toilet and point to it. Demonstrate tasks first.
- **Avoid quizzing and arguing.** Instead of questioning or correcting them, 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 the PLWD isn't trying to be difficult—the disease has changed their brain. Try your best not to take negative communication 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. Reach out today!

Explore information, resources and services at **alz.org** or call the 24/7 Helpline at 1-800-272-3900.

RESOURCES

WHAT IS DAKOTA AT HOME?

Dakota at Home, South Dakota's Aging and Disability Resource Center, is a free resource to help connect older adults, adults with disabilities and their caregivers to the long term services and supports they need to continue living at home or in their community.

AVAILABLE SERVICES

We can help connect you to a variety of services and resources.

Home Care Services
Provides services to help older adults or adults with disabilities stay in their home based on their needs.

Safety & Help Moving Around
Provides services in the home to help keep an aging adult or an adult with disabilities safe, secure and independent.

Nutrition & Meals
Provides healthy meals, nutrition screenings, assessments, education and counseling.

Senior Health Information and Insurance Education (SHIINE)
Provides information to individuals about Medicare benefits and how to protect benefits from fraud.

Caregiver Support
Offers caregivers the resources and tools they need to provide care and gives them an opportunity to take a break from caregiving or receive financial assistance for providing care to a family member. These services also provide aging adults and adults with disabilities time to socialize and receive support in a community setting through Adult Day Services.

Residential Living Services
Provides services and supports in assisted living centers, community living homes and nursing facilities.

Ombudsman Program
Provides advocacy, education and information for residents, family and staff in long term care settings.

Adult Protective Services
Provides interventions to protect vulnerable adults from abuse, neglect or exploitation.

OTHER RESOURCES

Dementia & Driving

Caregiver Classes & Support

Gun Locks & Medication Lock Boxes

Organizing Legal & Financial Documents

LOCAL/REGIONAL

To locate resources near you, contact Dakota at Home, South Dakota's Aging and Disability Resource Center with the Department of Human Services, for free options planning.

Call Dakota at Home
1-833-663-9673

Visit Website
dhs.sd.gov/ltss/dakota-at-home

Dakota at Home Online Resource Directory
dakotaathome.sd.gov

Alzheimer's Association, SD Chapter
Community education, support groups, family consultations.
24/7 Help: 1-800-272-3900 | **alz.org**

Active Generations, CAREgiver Outreach Program
East River caregiver support and education.
605-333-3319 | **caregiverssd.org**

Black Hills Center for Aging
West River Caregiver support and education.
605-791-0436 | **blackhillscfa.org/caregiver-support**

Black Hills Memory Café
Social engagement for people with memory loss together with their care partner(s).
605-484-9435 | MemoryCafeBH@gmail.com | **bhmemorycafe.org**

Helpline Center
Statewide resource connecting individuals to resources.
Dial 211 | help@helplinecenter.org | Text zip code to 898211
helplinecenter.org

SDSU Extension Gerontology
Caregiving for Rural Families courses, dementia programming, aging support statewide.
605-394-1722
extension.sdstate.edu/wellness/older-adults
extension.sdstate.edu/tags/family-caregiving

Sioux Falls VA Health Care System
Caregiver Support Program—caregiver education and support groups
605-336-3230
va.gov/sioux-falls-health-care/health-services/caregiver-support

VA Black Hills Health Care System
Caregiver Support Program—multiple locations throughout the Black Hills area.
605-206-1871

SUPPORT GROUPS

Local – Regional – Online

To locate resources near you, contact Dakota at Home, South Dakota's Aging and Disability Resource Center with the Department of Human Services, for free options planning.

Call Dakota at Home
1-833-663-9673

Visit Website
dhs.sd.gov/ltss/dakota-at-home

Dakota at Home Online Resource Directory
dakotaathome.sd.gov

Alzheimer's Association, SD Chapter
Local support groups may be available in Aberdeen, Brookings, Canton, Huron, Pierre, Rapid City, Sioux Falls, Spearfish, and Vermillion.
605-339-4543 | **alz.org/sd/support**

CAREgiver Outreach Program, Active Generations
East River caregiver support and education.
605-333-3319 | **caregiverssd.org**

Black Hills Center for Aging
West River caregiver support and education.
605-791-0436 | **blackhillscfa.org/caregiver-support**

Statewide Support Groups

- Trualta
  Online support group and learning platform for South Dakota caregivers.
  sd-caregivers.trualta.com
- Dementia Minds
  National Council of Dementia Minds
  dementiaminds.org/dementia-minds

**All support groups are free to attend. Information listed is not intended to be a comprehensive list of all available support groups.*

HEAD FORWARD
SOUTH DAKOTA

Supporting Your Brain Health Journey

A dementia diagnosis can feel overwhelming, but you are not alone. Head Forward South Dakota, a program through the South Dakota Department of Health, is here to help find support and resources.

What We Do

- Promote healthy habits that support brain health.
- Encourage early detection and diagnosis of dementia.
- Support families and caregivers through every step of the disease.
- Improve quality of life for caregivers and people living with dementia.

SD Healthy Brain Coalition

Head Forward SD created the SD Healthy Brain Coalition. By working together with local caregivers, healthcare providers, community partners, and others, the SD Healthy Brain Coalition is providing the best possible resources to promote brain health across the lifespan and provide support to all those affected by dementia.

We Can Support Your Journey

Visit **HeadForward.SD.gov** to get started.

- Join the Healthy Brain Coalition and help make a difference.
- Sign up for our quarterly newsletter for tips, updates, and education opportunities.
- Find resources and support for families and caregivers.
- Increase awareness of early warning signs and the benefits of early detection.
- Access trusted resources on brain health and practical lifestyle strategies.

A dementia diagnosis is life-changing, but it doesn't need to define your life. With the right tools and support, you and your family can continue to live well and embrace a meaningful future.

ACTION STEPS SUMMARY

☐ **Have family meetings along the way to discuss what's happening and how to support the person with memory loss and care partner**. Important topics of discussion include:

- Encouraging a diagnosis
- Discussing safety issues, such as driving and safe medication use
- Needing support with financial or legal planning
- Coordinating care at home
- Considering safe living situation and options
- Discussing ways to support the primary care partner/caregiver

☐ **Make and update a back-up plan** along the way to be used if something happens to the care partner/caregiver.

☐ **Obtain a medical assessment of memory loss/cognitive impairment and diagnosis for the person living with dementia (PLWD).** This opens the door to necessary planning. The process should start with your health care practitioner, and may involve other specialists such as a geriatrician, a neurologist, and/or a neuropsychologist.

☐ **Complete health care planning documents.** The PLWD should have:

  ☐ A Health Care Directive (also called a "living will" or "advance directive" regarding treatment preferences)

  ☐ A Durable Power of Attorney for Health Care, appointing a health care "agent." Complete a General Durable Power of Attorney document. In this document, the PLWD appoints an "agent" to assist with financial and related matters. **theconversationproject.org/wp-content/uploads/2020/12/DementiaGuide.pdf**

  ☐ A MOST (Medical Orders for Scope of Treatment). Discuss and complete with your physician, if appropriate.

To learn more, visit: **doh.sd.gov/healthcare-professionals/advance-directives-and-medical-orders**

- ☐ Complete an estate plan. The person living with dementia's (PLWD) estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- ☐ Complete end-of-life planning and document how the PLWD 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 the PLWD the issue of when to discontinue driving. If needed, enlist help of a healthcare provider, a professional driving evaluation through the Department of Transportation, or call the Alzheimer's Association for more ideas.
- ☐ Develop a plan for caregiver self-care to prevent burnout. To learn more, visit **alz.org/help-support/caregiving/caregiver-health**.

LTSS
LONG TERM SERVICES & SUPPORTS
+
South Dakota
DHS

dhs.sd.gov/ltss/dakota-at-home

Adapted with permission from the Washington State Dementia Action Collaborative's Dementia Road Map: A Guide for Family and Care Partners and Virginia's Alzheimer's Disease and Related Disorders Commission

This project was supported, in part by grant number 90ADPI0130, from the U.S. Administration for Community Living, DHHS, Washington, D.C. 20201.