Kansas Dementia Road Map

A Guide for People Impacted by Dementia

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Kansas

Department for Aging
and Disability Services

Adapted with permission from the
Dementia Action Collaborative's
Dementia Road Map:
A Guide for Family and Care Partners

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Welcome

Caring for a person living with memory loss or dementia is a journey, one that can last for many years, and is filled with twists and turns. The journey is not a straight path through stages—each person with Alzheimer's or other type of dementia may progress differently and in their own time. Family members who are companions on this journey will need information, support, and guidance along the way.

Most families report they are not prepared for life with dementia and that they would welcome some type of "Road Map." This document is designed to be just that. It provides a look at the big picture and the road ahead—and offers direction and tips about what to expect, what decisions lie ahead, and what steps to take.

Guides for the journey

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

- **Area Agencies on Aging** are a trusted source of information and assistance, where older adults can turn to find specialized information, supports and service options in their area. They also offer Family Caregiver Support Programs that assist family members as they are helping a loved one with dementia or other conditions. To find your local agency see the Area Agency on Aging location map on page 26.
- **The Alzheimer's Association** is a worldwide voluntary health organization dedicated to Alzheimer's care, support, and research. Consult the Alzheimer's Association for education classes about Alzheimer's disease, what to do after a diagnosis, how to find a support group, and how to navigate the Alzheimer's journey. Call their 24/7 Helpline at 800-272-3900 or see Resources on the inside back cover.
- **KU Alzheimer's Disease Research Center (ADRC)**. When you connect with the ADRC, you gain access to groundbreaking studies as well as exceptional care, valuable information, and supportive resources. If you have concerns about memory changes, a dementia diagnosis, or how to best care for a friend or family member call 1-913-588-0555 or see Resources on the inside back cover.

Terminology:

Throughout this document, a variety of terminology is used:

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

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

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

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

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

Younger-Onset Alzheimer's Disease

Alzheimer's disease that appears in people under the age of 65 is called Younger-Onset Alzheimer's disease. Alzheimer's disease is often thought of something that only affects older people, but a small number of people show symptoms in their 40s and 50s or even younger. Other dementias may also appear in those under the age of 65, such as Frontotemporal dementia.

There are unique considerations for individuals with a diagnosis of younger-onset Alzheimer's disease. For information see Resources on the inside back cover.

The Social Security Administration (SSA) has added younger-onset Alzheimer's to the list of conditions under its Compassionate Allowance program, giving those with the disease expedited access to Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

Older American Act programs available through your local Area Agency on Aging were opened in 2020 to those diagnosed or caring for people diagnosed with Alzheimer's disease of any age. Contact your Area Agency on Aging for information on caregiver supports available.

Worried About Memory Loss

> *"Navigating through this path, has been referred to as "building an airplane in the air", it is extremely difficult."*
>
> **– Kansas Caregiver**

You may be wondering

Is everything OK?

- Should I or my loved one be checked by a health care professional?
- Have I, or has my loved one, completed an annual wellness exam or cognitive evaluation?
- What if my loved one won't go to a health care professional?

Worried about memory loss in a loved one or yourself?

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

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

- Find out what may be causing the problems— there are reasons for memory loss and confusion that are treatable. Some conditions such as normal pressure hydrocephalus, thyroid problems, or a vitamin deficiency, are treatable or reversible. Other conditions, such as depression or delirium, can seem like dementia.
- Access to treatment options if diagnosed with dementia.
- Early diagnosis allows the person and their family more time to educate themselves, seek support that works for them, and make informed decisions and plans for future care.
- The opportunity to participate in a wider variety of clinical trials.

What should you expect in this stage?

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

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

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

Talking to your Doctor about Memory Loss

Effective communication with your doctor is important when you are seeking a diagnosis for memory loss. Be prepared, speak up, listen, take notes and ask questions. For information on choosing a doctor or questions to ask see Resources on the inside back cover.

What you can do:

- Learn about warning signs and normal changes with aging. See the "10 Warning Signs" on page 21.
- If you're worried about changes in yourself, consider sharing your concerns with family, friends, or your health care professional.
- Keep track of changes you notice. If your loved one doesn't bring it up, find the right time and a sensitive way to discuss these changes with them.
- Ask your loved one to have a complete medical check-up. It's important to know if memory and thinking changes may be caused by something that could be treated or reversed.
- If your loved one is resistant to a medical check-up, enlist the help of trusted family or friends who may be able to encourage this.
- Ask your loved one if you can attend and participate in their medical appointments, and to be included on a HIPAA or medical release form to access their health information.
- Call and ask your loved one's health care professional for the Medicare Annual Wellness visit (if they are on Medicare). This should include a cognitive assessment along with other screenings, such as for hearing loss. Feel free to share with the professional what you've noticed about changes in memory or thinking – either in person, via phone or in a letter.
- If you don't feel comfortable with your loved one's current health care professional, try to find a new one. Most primary care professionals can diagnose dementia. But if you're looking for a specialist, contact the Alzheimer's Association or Area Agency on Aging to help identify providers in your area.
- If you know or suspect your loved one has hearing loss, get it checked and addressed— hearing loss makes it harder for a person with memory loss or confusion to communicate. This can lead to misunderstandings and social isolation.

What you can do: *continued*

- Make sure both you and your loved one are making healthy lifestyle choices:
  - Stay active and engaged in social groups, arts, and other activities of interest.
  - Eat a healthy diet.
  - Be physically active.
  - Get plenty of sleep.
  - Minimize stress.
- Make it a priority to begin and/or complete both financial and health care advanced planning documents. While all adults should have a plan in place in the event of one's disability or death, such planning is even more important for anyone beginning to experience changes in memory or thinking abilities. While such changes may or may not end up being dementia, it is critical to complete this planning while your loved one has the ability to do so.

Clinical Trials

Participating in clinical trials helps to advance research in treatments, prevention or a cure for Alzheimer's and other related dementias. Find out more at the Alzheimer's Association's TrialMatch, a free clinical trial matching service, connecting individuals with Alzheimer's, caregivers and healthy volunteers to current research studies. For more information, call 1-800-272-3900 or ask your health care provider about clinical research opportunities in your area.

Action Steps *The following steps are important at this point:*

☐ **Obtain a medical assessment** to find out what may be causing the problems.

☐ **Complete advanced health care planning documents.** You and your loved one should have:

  ☐ A Living Will, expressing your health care wishes.

  ☐ A Durable Power of Attorney for Health Care, appointing a health care "agent."

☐ **Prepare your financial affairs.** This includes legal documents such as a will or trust that direct the disposition of their property upon death. You can also appoint an "agent" to assist in your financial affairs by competing a General Durable Power of Attorney.

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

Mild Cognitive Impairment (MCI)

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

You may be wondering

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

What should you expect in this stage?

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

You may:

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

What you can do:

- If not yet evaluated, ask your loved one's health care professional for the Medicare Annual Wellness visit—it includes detection of cognitive impairment along with other screenings.
- Ask your loved one if you can attend and participate in their medical appointments, and to be included on a HIPAA or medical release form to access their health information.
- Make it a priority to begin and/or complete both financial and health care advanced planning documents. While all adults should have a plan in place in the event of one's disability or death, such planning is even more important for anyone beginning to experience changes in memory or thinking abilities. While such changes may or may not end up being dementia, it is critical to complete this planning while your loved one has the ability to do so.
- Inquire about lifestyle changes that may be helpful to overall wellness and functioning.
- Learn more about Mild Cognitive Impairment (MCI).

What you can do: *continued*

- Consider keeping a notebook about your loved one's changes and needs (such as new or different behaviors, medication changes or effects, abilities to take care of finances or appointments)
- Tell your own health care provider that you are caring for a loved one with cognitive impairment so they can be aware of potential health-related risks.
- Instead of thinking that your loved one should just "try harder"—remind yourself that they are doing the best they can.
- Be generous with your patience. Review the "10 Caregiver Principles" on page 23.
- Consider paying bills and shopping together so your loved one can have successes.
- Consider enrolling in a clinical trial or research study on dementia, see page 6
- Begin investigating Family and Medical Leave Act (FMLA) options and other respite services that can support you with caring for your loved one.

To help your loved one:

- Support them in managing any other health issues. This may include helping them to manage medications.
- Encourage a healthy lifestyle including regular exercise, a healthy diet, and social activities.
- Encourage the use of long-time skills, like playing the piano, singing, typing, crafts, or speaking a second language.
- Share (and read) the booklet—*Living Well with MCI or Early Dementia* from the Alzheimer's Association. See Resources on the inside back cover.

Action Steps *The following steps are important at this point:*

Remember! If your loved one has not yet had a medical assessment, contact their health care professional.

☐ **Learn more about MCI**. Contact the Alzheimer's Association or KU ADRC.

☐ **Complete advanced health care planning documents.** You or your loved one should have:

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

  ☐ **A Durable Power of Attorney** for Health Care and Financial, appointing a health care "agent."

☐ **Prepare your financial affairs.** This includes legal documents such as a will or trust that direct the disposition of their property upon death. You can also appoint an "agent" to assist in your financial affairs by competing a General Durable Power of Attorney.

☐ **Consider participating in a Clinical Trial**. See Resources on the inside back cover.

☐ **Have a family meeting.** Discuss what's happening, and ways to support the person with memory loss, such as: encouraging a check up with a health care provider, managing safe medication use, and/or helping with finances or legal planning.

Early-Stage Dementia

> *"This is my full-time job now."*
>
> **– Kansas Caregiver**

You may be wondering

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

What should you expect in this stage?

Your loved one has difficulty accomplishing some activities. They may also:

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

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

If I Live Alone

Many people diagnosed with Alzheimer's continue to live successfully on their own during the early stage of the disease. Making simple adjustments, taking safety precautions, and having the support of others can make things easier.

- If you live alone, it's crucial to make legal and financial plans now while you can participate in making decisions to ensure that others know your wishes and know what to do.
- There are several safety issues to consider that may help you maintain your independence for as long as possible:
  - Driving, home safety, and fall risks.
  - Self-care and day-to-day needs.
  - Isolation and loneliness

Ask for help. It can be difficult to know when to ask for help or to admit that help is needed. You may feel that by asking others for help, you will become too dependent on others. Have a conversation with family and friends about the daily tasks that have become more difficult for you to complete. If you don't have family, reach out to Area Agency on Aging or Alzheimer's Association for help with a care plan.

You may:

- Feel optimism and/or an early sense of loss and grief.
- Notice a need to provide more reminders and supervision.
- Want to ask for help around the home like housekeeping, errands, laundry, or yard care.
- Be impressed by your loved ones ability to adapt and grow, in the midst of challenges.

What you can do:

- Be an advocate for the right diagnosis and best health care. If you're not happy with current care, find a health care professional that will work with you and your loved one together.
- Ask your loved one if you can be included on a HIPAA or medical release form to access their health information. Go along on medical appointments. If they do not want this, try calling the practitioner ahead of appointments to share concerns.
- Make it a priority to begin and/or complete legal, financial, and advance care planning, including essential planning documents. While all adults should have a plan in place in the event of one's disability or death, such planning is even more important for anyone beginning to experience changes in memory or thinking abilities. It is critical to complete this planning while your loved one has the ability to do so.
- Learn all you can about the disease and tips for communicating supportively with your loved one. See Communication Tips on page 22.
- Put safety measures in place before they're needed related to falls, wandering, medication use, harmful cleaning products, guns, power tools, etc. Find information on safety in the Resources section on the inside back cover.
- Embrace the good days and prepare yourself for the stormy ones.
- Make your life a no guilt zone.
- Keep up health and wellness appointments for yourself.
- Seek out support and reassurance: talk with others who have had a similar situation. See Resources on the inside back cover.
- Explore how your loved one wants to live at the end of their lives. Read the *Conversation Starter Kit for Families of Loved Ones of People with Alzheimer's Disease or other Forms of Dementia*. See Resources on the inside back cover.

To help your loved one:

- Provide *Living with Alzheimer's: Taking Action Workbook*. Find this in the Resources section on the inside back cover.
- If your loved one is still driving, review together the booklet *At the Crossroads: Family Conversations about Alzheimer's, Dementia and Driving* which may be found in the Resources section on the inside back cover.
- Create and stick to simple routines.
- Monitor that medications are taken properly.
- Encourage them to continue activities of interest. Look for ways to modify them as needed.
- Promote the best functioning possible. Get hearing loss and vision checked regularly. Make sure hearing aids and glasses are in good condition and used as needed.
- Resist the urge to step in and do things for them; allow more time, and occasional errors.
- Encourage them to attend an early-stage support group and seek out dementia-friendly recreation activities.
- Consider enrolling in a clinical trial through TrialMatch on page 6.
- When you see behaviors that are "out of character," do NOT take these personally—recognize it's the disease.
- Help family and friends understand how to communicate and interact—if needed you can share what they like to do, how to start a conversation, the need to avoid correcting and arguing.
- Consider ways to protect yourself and your loved one from financial missteps and exploitation such as removing your loved one's credit cards (or lower credit limits) and other key wallet documents.

Services to consider:

- Support Groups
- Alzheimer's/dementia seminars and educational workshops
- E-Learning and online courses
- Get connected online—try the Alzheimer's Navigator or ALZConnected - online services offered through the Alzheimer's Association.
- Look into locator aids that use active-GPS capability (real-time tracker).
- Programs and services through your Area Agency on Aging.

Down Syndrome and Intellectual Development Disabilities (I/DD)

People with IDD are living longer and are at an increased risk of developing dementia. It is estimated that 50% or more of people with Down syndrome will develop dementia due to Alzheimer's disease as they age, with symptoms starting in their 40's and 50's. Cognitive changes are sometimes not recognized as symptoms and can be difficult to diagnose. Care for people with Down syndrome and I/DD and dementia is especially challenging due to the intellectual, cognitive and communication impairments associated with Down syndrome that are present in addition to the cognitive impairments of dementia. For more information see Resources on the inside back cover.

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

You are not alone! Caring for someone with dementia can be overwhelming. Finding local support is important to maintain a good quality of life for both the person with dementia and the caregiver.

Contact one or more of the organizations listed below to find a virtual or in person support group:

- **Area Agency on Aging** - see Area Agency on Aging location map on page 26.
- **Alzheimer's Association** - 1-800-272-3900
- **KU ADRC** - 1-913-588-0555
- **Veterans Caregiver Support** - 1-855-260-3274

Eldercare Locator

The Eldercare Locator is a public service of the U.S. Administration on Aging connecting you to services for older adults and their families. You can also reach us at 1-800-677-1116 or see Resources on the inside back cover.

Action Steps *The following steps are important at this point:*

See Action Steps on pages 6 and 8, and do the following:

☐ **Learn more about Alzheimer's disease or other related dementias.** See Resources on the inside back cover.

☐ **If your loved one is still driving,** review together the booklet *At the Crossroads: Family Conversations about Alzheimer's, Dementia and Driving* which may be found in the Resources section on the inside back cover.

☐ **Be Safe** – find safety tips at home and while traveling in the Resources section on the inside back cover.

☐ **Make sure your loved one** either carries ID or wears Medical ID jewelry.

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

☐ **Stay Healthy**… be active, eat well, stay social and get regular medical care.

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

☐ **Make a back-up plan** to be used if something happens to you.

☐ **Find Support** for you and / or your loved one; see support options in the Resources section on the inside back cover.

☐ **Contact your local Area Agency on Aging** for information about local services and the Family Caregiver Support Program.

Mid-Stage Dementia

You may be wondering

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

What should you expect in this stage?

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

- Have more trouble with memory.
- Have problems planning and following instructions.
- Not recognize familiar people.
- Forget how to initiate routine tasks or how to complete them, including health and hygiene care.
- May resist bathing or other personal care. May have episodes of incontinence.
- Have abilities that vary from one day to the next.
- Complain of neglect or blame others when things go wrong.
- Lack judgment and develop the following behaviors:
  - Trouble sleeping
  - Apathy, passivity
  - Irritability, aggressive talk and actions
  - Clinging (following you around)
  - Repetitive questions
  - Wandering
- Have delusions (false beliefs) or hallucinations (seeing/hearing things that aren't there).
- Have more problems with balance (increasing the risk for falls).
- Not be able to contribute to family life in traditional ways.
- Be increasingly sensitive to caregiver mood and behavior.

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

> *"My mood is his mood.*
> *All it takes is, "I love you."*
> *Enjoy the moments you have."*
>
> **– Kansas Caregiver**

You may:

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

What you can do:

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

To help your loved one:

- Encourage family and close friends to learn communication tips and techniques—and to help provide activities your loved one still enjoys.
- Try to provide kindness, understanding, and acceptance.
- Channel their energy—go for regular walks together, encourage them to help with chores like vacuuming, sweeping, folding laundry or gardening.
- Simplify tasks and activities, break into smaller steps—allow more time for your loved one to accomplish them.
- Reminisce—look at old photo albums, a memory book or old videos.
- Make sure your loved one gets ongoing medical care.
- If you notice any SUDDEN changes in behavior, call your loved one's physician—this can be a sign of an infection or other medical issue.
- Talk to their doctor about a referral to a Physical or Occupational Therapist for a home safety evaluation.
- Learn caregiving tips, safety information, common medical problems, and how to care for yourself in this comprehensive, easy-to-read guide from the National Institute on Aging - *Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide*. See our Resource list to see how to receive your copy.

Services to consider:

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

You may be thinking, “I need assistance, I can’t do this anymore”

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

- **Area Agency on Aging (AAA)** see AAA map on page 26
- **Alzheimer’s Association** at 1-800-272-3900

Action Steps

See Action Steps on pages 6, 8, and 13 and do the following:

☐ **Request** a home safety evaluation with a Physical or Occupational Therapist to make the home safer and home care tasks easier.

☐ **Update** your back-up plan to be used if something happens to you.

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

☐ **If help with financing care is needed,** contact your local Area Agency on Aging. See Area Agency on Aging location map on page 26.

☐ **Complete end-of-life planning.** Discuss and document how your loved one wants to live at the end of their life, including medical care wanted or not wanted, comfort measures, and palliative and hospice care.

Late-Stage Dementia

You may be wondering

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

What should you expect in this stage?

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

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

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

You may:

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

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

Reach out to others in a similar situation, a care coordinator, a counselor, other caregivers or a support group.

- Area Agency on Aging (AAA) See AAA map on page 26
- Alzheimer's Association at 1-800-272-3900
- KU ADRC at 1-913-588-0555

What you can do:

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

To help your loved one:

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

Services to consider:

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

Dementia Quick Reference

10 Warning Signs of Alzheimer's — *vs.* —	Normal Aging
Memory loss that disrupts daily life • *asking for information over and over again.*	Forgetting a name or word but remembering it later.
Challenges in planning or solving problems • *struggles working with numbers, counting change or following plans.*	Forgetting an ingredient in a recipe or slower response time.
Difficulty with tasks that are familiar • *trouble using a phone or remote, forgetting rules of a game or struggles with work duties.*	May need help with new technology, but still able to use with instruction.
Confusion with time or place • *struggles with loss of time or gets lost easily.*	Occasionally forgetting the date or going into a room and can't remember why, but remembering later.
Visuospatial problems • *trouble judging distance, may be falling more.*	Eyes aging normally, may need glasses.
Trouble speaking or writing words • *difficulty holding conversations or having trouble reading words.*	Forgetting a word or name but remembering it later.
Misplacing items and not being able to find them • *accusing others of stealing or hiding things.*	Losing something, but able to retrace their steps.
Changes in judgement • *making bad decisions or falling for scams.*	Making a bad choice, but learning from mistakes.
Withdrawal from social activities or work • *losing interest in hobbies or responsibilities.*	Skipping a social gathering once in awhile.
Mood and personality changes • *drastic changes in feeling confused, suspicious, angry, or sad.*	Being briefly irritated or anxious.

Make sure not to try and self diagnose after reading through these symptoms.
If you have concerns that you may be showing early signs of Alzheimer's disease, discuss what you are experiencing and feeling with your doctor.

Communication Tips

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

What you can do:

- **Be present.** Let your loved one know you're listening and trying to understand. Keep your voice gentle. Hold the person's hand while you talk. Smile, nod, make appropriate eye contact.
- **Show respect.** Offer your loved one undivided attention, don't multi-task. Include your loved one in conversations, don't talk about them as if they weren't there.
- **Avoid distractions.** Background noise, like TVs or radios can compete for attention.
- **Position yourself.** Be close enough to be heard and seen clearly. Sit or stand at the same level, rather than standing over them.
- **Get hearing checked regularly.** If the person uses a hearing aid, check that it is working and inserted properly. When speaking, turn your face towards them and make sure your face is in the light so they can easily see your lip movements.
- **Keep it simple.** Use short sentences. Ask one question or offer one instruction at a time. It usually helps to use "positives"—say "Let's go here" vs. "Don't go there." As the disease progresses, ask questions that require a yes or no answer.
- **Allow time and be patient.** Slow pace of speech slightly and allow time for the person to process and respond. Try to avoid interrupting. If you're feeling rushed or stressed, take some time to calm down.
- **Focus on feelings.** Listen for the meaning behind the words. Their tone or body language may provide clues. Respond to the emotions.
- **Offer comfort.** If a person with dementia is having trouble communicating, let them know it's OK. Offer hugs or hold hands as appropriate.
- **Use visual cues.** Gestures or other visual cues can help promote better understanding than words alone. Rather than asking if your loved one needs to use the toilet, walk them to the toilet and point to it. Demonstrate a task first.
- **Watch your tone and manner.** Try to keep your voice gentle. No one likes to be talked down to or criticized. Try not to sound "bossy." Use friendly facial expressions and non-verbal communication that conveys "calm." A person with dementia responds to others' moods, if you're upset, they may become upset too.
- **Avoid quizzing and arguing.** Instead of questioning or correcting your loved one, listen for the messages in what they're saying. Try to avoid arguing—no one will "win" and it will only lead to embarrassment, frustration, or anger.

It's important to remember that your loved one isn't trying to be difficult—the disease has changed their brain. Try your best not to take communications and behaviors personally. It's also important to know that these are offered as suggestions—we encourage you to forgive yourself when things don't go as well as you want them to. It can be helpful to talk with others in the same situation to get more ideas and support.

Caregiver Stress

What you can do:

- Make some time for self-care. This includes keeping up with your own doctor appointments, eating well, exercise, getting good sleep and staying social. You are better able to take care of others when your own physical condition is secure.
- Create a support system. Over time caregiving can take an emotional toll. Join a caregiver support group. Support groups are a chance to share your story and learn from others in similar situations. See support options in the Resources section on the inside back cover.
- Enlist others. Few people can do it alone. Even people who can't provide hands-on care may be able to take on tasks such as grocery shopping, meal prep or light housekeeping. If you don't have a group of family and friends to call upon contact your local Area Agency on Aging – see map on page 26.
- Take time for yourself. If you're caring for someone who needs constant attention, there is no question that you will need relief at some point. Just setting aside a few minutes for a walk in the park or a chat with a friend can make a world of difference. Learn more about Respite Care from your local Area Agency on Aging or Alzheimer's Association.
- Learn new caring skills. Learning more about dementia can ease stress and help you provide better care for your loved one. Go to the Alzheimer's Association's online "Caregiver Center" to find helpful tips on daily care such as activities, providing personal care and managing incontinence. See our Resource page on the inside back cover to learn more.

10 Caregiving Principles

1. ***Agree...*** never argue.
2. ***Redirect...*** never reason.
3. ***Distract...*** never shame.
4. ***Reassure...*** never lecture.
5. ***Reminisce...*** never say "remember."
6. ***Repeat...*** never say "I told you so."
7. ***Say "do what you can"...*** never say "you can't."
8. ***Ask...*** never command.
9. ***Encourage and praise...*** never condescend.
10. ***Reinforce...*** never force.

The Different Stages

Early Stage Alzheimer’s Disease

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

Middle Stage Alzheimer’s Disease

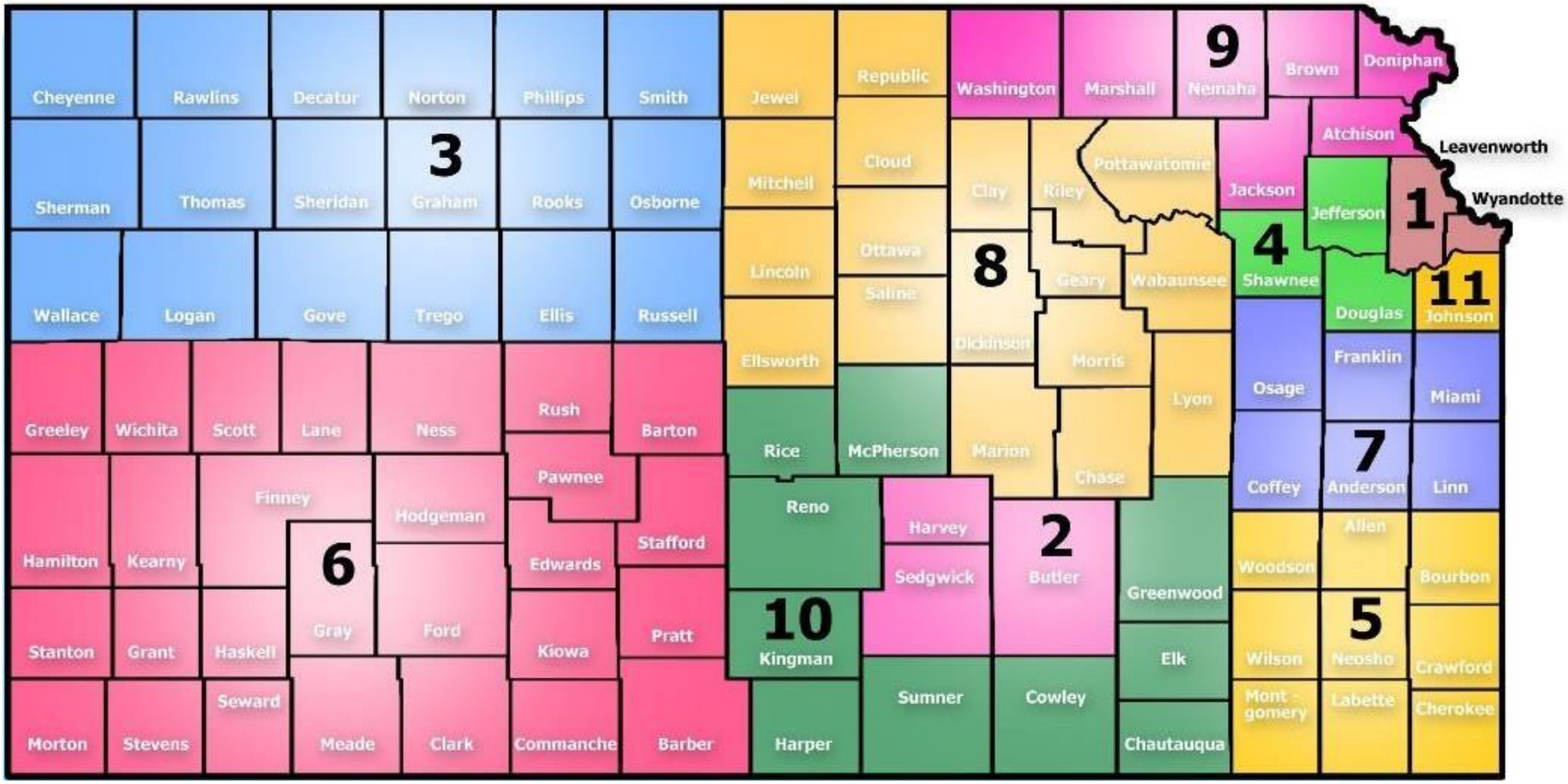
- Increasing needs for care and supervision.
- More trouble with memory such as own address or personal history.
- Problems organizing, planning, following instructions and solving problems.
- Not recognizing familiar people.
- More problems with balance (increasing the risk for falls.)
- May resist bathing or other personal care.
- Forgetting how to initiate or complete tasks, including health and hygiene 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).
- Not being able to contribute to family life in traditional ways.

Late Stage Alzheimer’s Disease

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

Action Steps Summary

- ☐ **Obtain a medical assessment** of memory loss/cognitive impairment and diagnosis for your loved one—this opens the door to necessary planning. This process should start with your health care practitioner, and may involve other specialists such as a Geriatrician, a Neurologist, and/or a Neuropsychologist.
- ☐ **Contact the Alzheimer's Association, Area Agency on Aging or KU Alzheimer's Disease and Research Center** for information and support.
- ☐ **Complete advanced health care planning documents.** You and your loved one should have:
    - ☐ A Living Will, expressing your health care wishes.
    - ☐ A Durable Power of Attorney for Health Care, appointing a health care "agent."
- ☐ **Prepare your financial affairs.** The estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- ☐ **Complete end-of-life planning** and document how your loved one wants to live at the end of their life, including medical care wanted or not wanted, comfort measures, and palliative and hospice care.
- ☐ **Consider participating in a clinical trial.**
- ☐ **Stay Healthy** by being active, eating well, staying social and getting regular medical care.
- ☐ **Make sure your loved one either carries ID** or wears medical ID jewelry.
- ☐ **Discuss with loved one the issue of when to discontinue driving.** If needed, enlist help of healthcare provider, a professional driving evaluation, or call the Alzheimer's Association for more ideas.
- ☐ **Find Support for you / and or your loved one;** see support options in the Resources section on the inside back cover.
- ☐ **If help with financing care is needed,** contact your local Area Agency on Aging. See map on page 26.
- ☐ **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 and discussing safety issues, such as driving and safe medication use.
    - ☐ Needing support with financial or legal planning.
    - ☐ Coordinating care at home.
    - ☐ Considering safe living situation and options.
    - ☐ Discussing ways to support the primary care partner/caregiver.
- ☐ **Request a home safety evaluation** with a Physical or Occupational Therapist to make the home safer and home care tasks easier.
- ☐ **Make and update a back-up plan** along the way to be used if something happens to you.
- ☐ **Discuss and seek palliative care** and hospice care.



Kansas Area Agencies on Aging Map

1 Wyandotte – Leavenworth
849 North 47th Street, Suite C
Kansas City, KS 66102
913-573-8531 / 888-661-1444

2 Central Plains
271 W 3rd Street N, Suite 500
Wichita, KS 67202
316-660-5120 / 855-200-2372

3 Northwest KS
510 W 29th Street, Suite B
Hays, KS 67601
785-628-8201 / 800-432-7422

4 Jayhawk
2910 SW Topeka Boulevard
Topeka, KS 66611
785-235-1367 / 800-798-1366

5 Southeast KS
1 West Ash
Chanute, KS 66720
620-431-2980 / 800-794-2440

6 Southwest KS
236 San Jose Avenue
Dodge City, KS 67801
620-225-8230 / 800-742-9531

7 East Central KS
117 S Main Street
Ottawa, KS 66067
785-242-7200 / 800-633-5621

8 North Central-Flint Hills
401 Houston Street
Manhattan, KS 66502
785-776-9294 / 800-432-2703

9 Northeast KS
1803 Oregon
Hiawatha, KS 66434
785-742-7152 / 800-883-2549

10 South Central KS
304 S Summit
Arkansas City, KS 67005
620-442-0268 / 800-362-0264

11 Johnson County
11811 Sunset Drive, Suite 1300
Olathe, KS 66061
913-715-8861 / 888-214-4404

ADRC Statewide Call Center
855-200-2372

RESOURCES

All the resources listed in this book, as well as this publication and tip sheets, can be found on the KDADS Website - Kansas Dementia Roadmap

kdads.ks.gov/dementia-roadmap

Or you can also scan this QR code.

Print copies of this publication and Resource Sheets are available at several organizations across the state.
You may reach out at the email below and we can let you know the closest location.

For feedback or questions:

KDADS.Dementia@ks.gov

This publication is a new resource. We welcome your feedback.

AD ASTRA PER ASPERA
Kansas
Department for Aging
and Disability Services