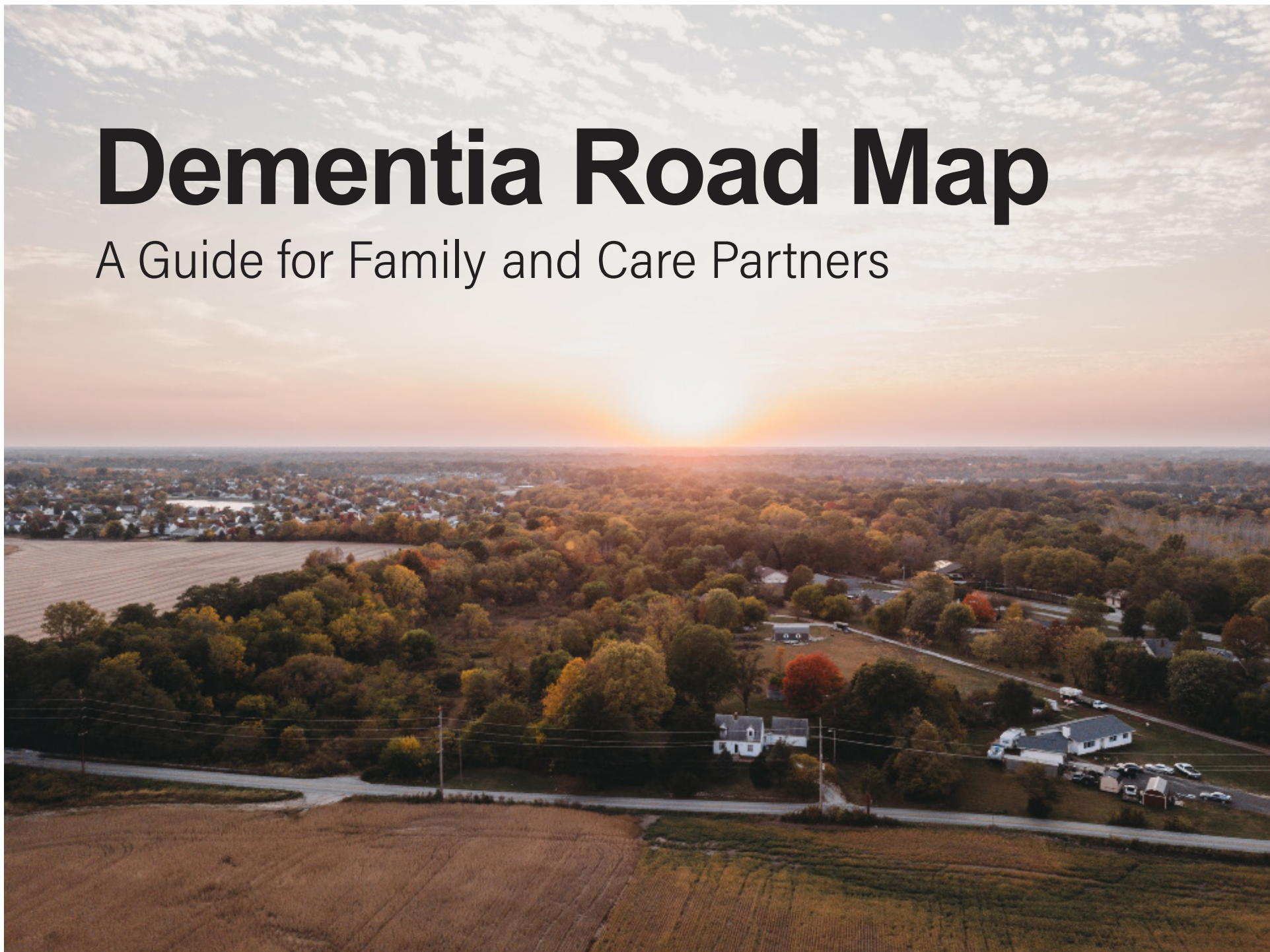


Dementia Road Map

A Guide for Family and Care Partners



Dementia Road Map: A Guide for Family and Care Partners

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DEMENTIA ROAD MAP OVERVIEW*

Wondering & Worried

Mild Cognitive Impairment (MCI)



- Is everything OK?
- Should a person with noticeable cognitive change be checked by a health care professional?
- How do I encourage someone with noticeable cognitive changes to go to a health care professional if they are resistant?

- Where do we go to get memory loss checked out?
- How can I help a person living with dementia with their memory and thinking?
- What can we do to promote the well-being of a person living with dementia?

* Stages for dementia are not diagnostic, rather stages can be used as a reference. Not all dementias stage the same and each person’s experience with dementia is different.



Early-Stage Dementia

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

Mid-Stage Dementia

- What can I do to make the home safer?
- What do we do if a person living with dementia won't stop driving?
- Where do we get help in coping with behaviors?
- What services might help, and where do I find them?

Late-Stage Dementia

- What can we do to promote quality of life?
- What kind of care is best for a person living with dementia?
- What do we want in terms of medical care at the end of a person living with dementia's life?



South Central Indiana Dementia Road Map

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

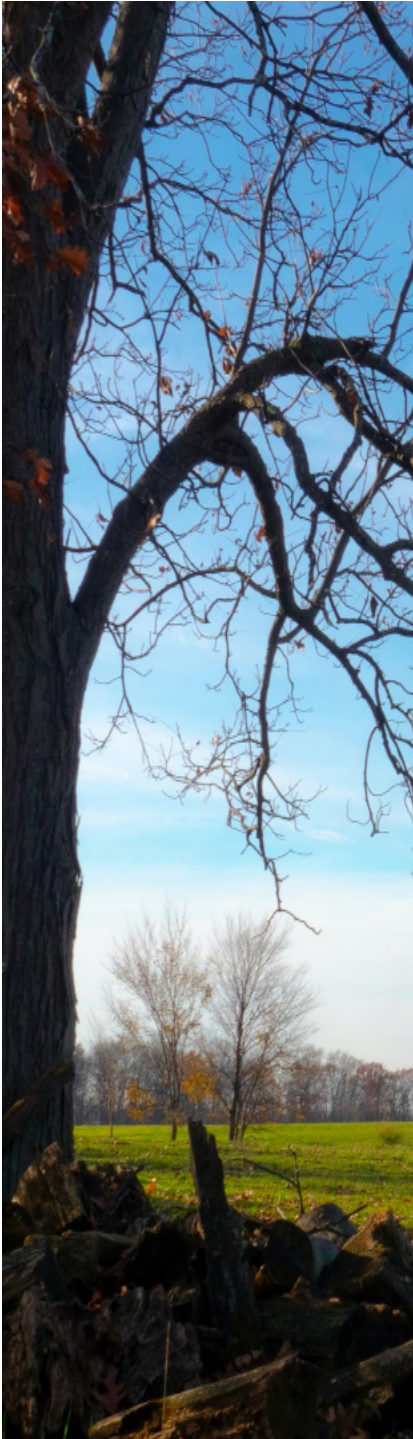
Most families and caregivers report they are not prepared for life with dementia and that they would welcome some type of “Road Map.” This document is designed to be just that. It provides a look at the big picture and the road ahead—and offers direction and tips about what to expect, what decisions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

Worried about memory loss in a loved one?

If you’re worried about the person living with dementia’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:

- Some forms of memory loss and confusion are treatable. Some conditions that cause dementia-like symptoms, such as normal pressure hydrocephalus, thyroid problems or a vitamin deficiency, are treatable or reversible.
- If diagnosed, it is best to find out the specific type of dementia and get help early in the disease process. A health care professional can provide better clinical care for all your medical conditions with a diagnosis when they understand what is happening.
- You, the person living with dementia, and other family members can more easily plan for the future when you know what you are dealing with. A diagnosis makes taking the next steps a bit clearer.



Guides for the Journey

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

- Area Agencies on Aging (AAAs) are trusted sources of information and assistance where older adults can turn to find specialized information, support, and service options in their area. They also offer Family Caregiver Support Programs that assist family members as they are helping a loved one with dementia or other conditions. AAAs are sometimes known as “Aging and Disability Services” or “Aging and Long Term Care”. For more information visit www.iaaaa.org or call 317.205.9201
- The Alzheimer’s Association has free literature on all-things dementia available in English and Spanish, 24/7 phone support (in a caller’s preferred language through a translation service), the latest information on brain health, available medications for people with dementia, support groups, trainings, and care consultation to help with decision-making. Visit: www.alz.org/indiana or call the 24/7 HELPLINE 800.272.3900.
- Another resource for the south central region of Indiana is Dementia Friendly Bloomington (dfbloomington.org) and Alzheimer’s and Dementia Resource Service of IU Health (iuhealth.org/in-the-community/south-central-region/alzheimers-resource-services)

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.
- PLWD—this term refers to a person living with dementia.



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

Dementia

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 or a specific diagnosis, 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.

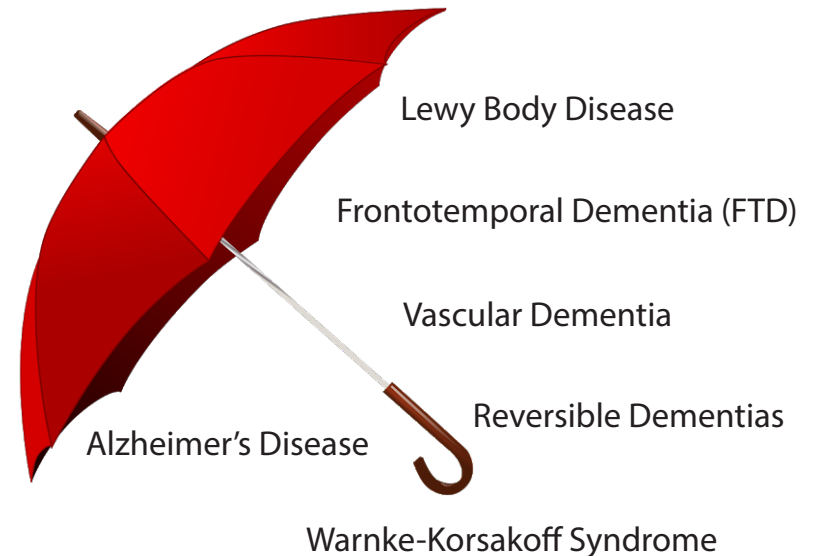
Alzheimer's

Alzheimer's disease is the most common cause of dementia. It is commonly characterized by a slow degeneration.

Other Common Dementias:

There are several types of dementias: Vascular, Lewy Body, Wernicke-Korsakoff are also some common types of dementias that have variant symptoms and can be caused by different conditions such as blood flow to the brain or over use of drugs and alcohol.

DEMENTIA



Reversible Dementias:

The medical term for this is commonly known as delirium. This is usually an acute change in mental condition that needs medical intervention. Delirium can be caused by many things such as but not limited to medication interactions, infection, lack of sleep, dehydration, malnutrition, changes in sugar and even untreated depression.



Wondering & Worried

“There is a difference between normal aging and abnormal aging. Just because someone is experiencing brain change does not mean it is a dementia.”

It is a good practice to ask your physician, for yourself and the person with dementia, to begin receiving cognitive evaluations each year starting at the age of 50. This will help you detect any changes early and may even detect something else that may be going on and could prevent progressive damage done to the brain. Some conditions could become irreversible in the future if not corrected.

Check out page 28 for 10 Warning Signs of Alzheimer’s.

You may be wondering...

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

What should you expect in this stage?

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

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

Your loved one is likely concerned about changes they are noticing but may not discuss them. Other friends and family may or may not see or notice any changes.

What you can do:

- Learn about normal changes with aging and those that indicate a need to get a check up ([See the “10 Warning Signs” on page 28](#)).
- Keep track of changes you notice. If the person you are concerned about doesn't bring it up, find the right time and a sensitive way to discuss these changes with them—get it out in the open to normalize the conversation about brain health and changes you are noticing. You could start the conversation by pointing out concerns of promoting your own brain health to let them know they are not alone.
- Ask the person you are concerned about to have a complete medical check-up and even volunteer to do it with them so they know that they are not alone. It's important to know if memory and thinking changes may be caused by something that could be treated or reversed. Even if not, it's best to know what you're dealing with for both now and in the future.



- If the person you are concerned about is resistant to a medical check-up, enlist the help of trusted family or friends who may be able to encourage this.
- Ask for a Medicare Annual Wellness exam for the person you are concerned about (if they are on Medicare) as it includes detection of cognitive impairment along with other screenings. Feel free to share with the professional what you've noticed either in person or in a letter prior to the appointment.

What you can do (continued):

- If both of you are uncomfortable with your current health care professional, discuss finding a new one. Most primary care professionals can diagnose dementias. If you're looking for a specialist, contact the Alzheimer's and Dementia Resource Service of IU Health to help identify providers in your area.
- If hearing loss is a concern, have hearing checked and addressed. Hearing loss can lead to misunderstandings and social isolation especially for people living with dementia. Additionally, hearing loss may seem as though a person has dementia but they are actually having changes in hearing and communication instead.
- For any of us as we age, we should make it a priority to begin and/or complete legal, financial and advance care planning.
- While all adults should have a plan in place in the event of one's disability or death, 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 you or the person with cognitive changes are able to do so.
- Make sure both you and the person living with dementia are making healthy choices:
 - Stay active in social groups, arts and other activities of interest.
 - Eat a balanced diet with fruits & vegetables and food low in saturated fat.
 - Be physically active.

"I needed to know how to access resources in my community for my mother who has dementia. Seeing her doctor was our first step." - David A.



In these documents, a person appoints an “agent” to assist with financial and related matters.

Estate planning may include legal documents such as a will or a trust that direct the disposition of their estate upon death.

Action Steps

The following steps are important at this point:

- Obtain a medical assessment to find out what may be causing the problems.
- Complete health care planning documents, such as:
 - Appointment of Health Care Representative and Power of Attorney for Health Care, appointing a health care “agent.”
 - Living Will Declaration, which allows a person to state treatment preferences if they are in an end of life situation.
 - Indiana POST form (Physician Order for Scope of Treatment). Discuss with a physician when it’s the right time to complete.
 - Durable Power of Attorney
- Complete a General Durable Power of Attorney document. In this document, a person appoints an “agent” to assist with financial and related matters.
- Complete an estate plan. A person’s estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- Have a family meeting to discuss what’s happening, and necessary next steps to take as a family.



Mild Cognitive Impairment (MCI)

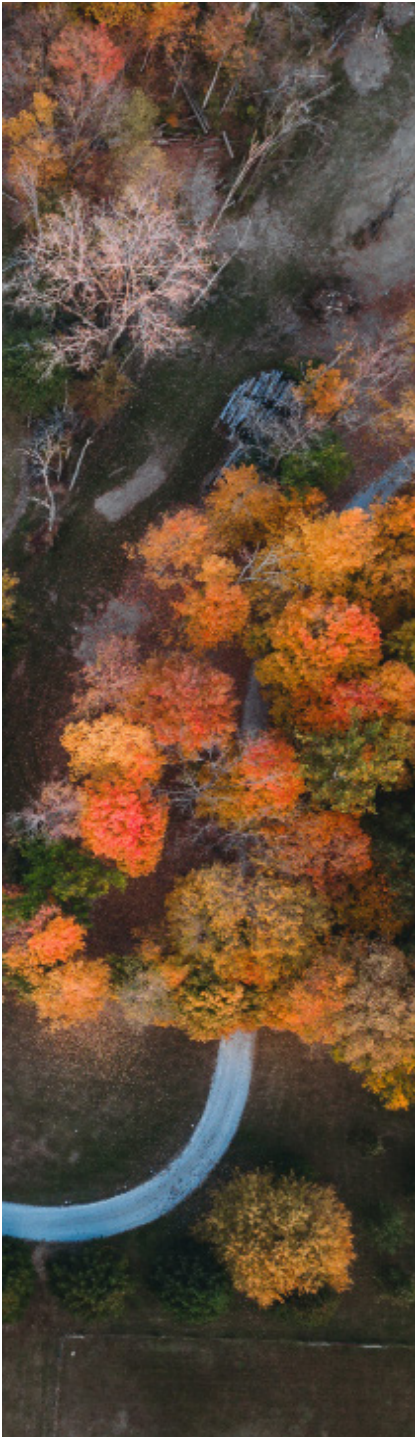
Mild Cognitive Impairment (MCI) is a slight but measurable decline in cognitive abilities that includes memory and thinking. MCI is not dementia. While a person with MCI has an increased risk of developing dementia, this may or may not occur.

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 a person living with dementia's well-being?

What should you expect in this stage?

The person with MCI or early stage dementia is still independent and may be able to do many things for themselves, however, they could experience increased difficulty paying bills, preparing meals, shopping, and driving. They may have trouble recalling details, may display less ambition, may have fluctuating emotions, and could either become resistant to help to try to do more tasks themselves. They also could become more reliant on others. You both may have better success when you create familiar routines and habits.



You may:

- Feel overwhelmed and irritated with your loved one's differing abilities.
- Feel compassion or a feeling of loss for a loved one's changes. Grief can come and go for you and the person living with dementia.
- Find that other friends and family may not notice changes at first in the person with dementia or understand your concerns. Sometimes they may not know how to respond or help and begin to distance themselves or seem indifferent due to lack of knowing what to do. It is a good idea to speak with your closest friends and family to discuss what you've learned from the healthcare provider. Dementia affects friends and family and they will need to be aware of how to support you both for future changes and challenges you may face together.

What you can do:

- If not yet evaluated, ask the person you're concerned about's health care professional for the Medicare Annual Wellness exam—it includes detection of cognitive impairment along with other screenings.
- Ask the person with dementia if you can attend and participate in their medical appointments to help them remember what their healthcare provider is explaining. If they agree, be respectful of the person's right to know about their results and allow them to tell their story to their healthcare provider without interruption.



- Inquire about lifestyle changes that may be helpful to overall wellness and functioning.
- Learn more about Mild Cognitive Impairment (MCI).
- Consider keeping a notebook about the person with dementia's changes and needs (This could be beneficial for your loved one to do as well to help you understand their challenges and changes from their perspective).
- 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 that could develop with stress.
- Instead of thinking that the person with dementia should just "try harder"—remind yourself that they are doing the best they can.
- Be generous with your patience.
- Consider paying bills and shopping together if this becomes a concern, so the person living with dementia can be supported and have success.
- Find out about local support groups for the both of you. and find time to get acquainted.



Action Steps

The following steps are important at this point:

Remember! If the person living with dementia has not yet had a medical assessment, contact their health care professional, a Geriatrician, a Neurologist, and/or a Neuropsychologist.

- **Discuss with your loved one and the medical professional** when to make the decision to discontinue driving for safety. Request a driving test if needed.
- **Complete health care planning documents. A person should have:**
 - An Advance Directive (which includes a living will, health care representative, and/or Durable Power of Attorney)
 - Provide copies of these documents to your medical providers, health care representative, and support partners.
- **Complete a General Durable Power of Attorney document.** In this document, a person appoints an “agent” to assist with financial and related matters.
- **Complete an estate plan.** A person’s estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- **Encourage other family and friends** to visit regularly and to seek support and education about dementia to understand your situation better.
- **Have a family meeting** to discuss what’s happening and ways to support the person with memory loss, such as: encouraging a check up with a health care provider, managing safe medication use, and/or helping with finances or legal planning.

To help a person living with dementia:

- Encourage a healthy lifestyle including regular exercise, a healthy diet, and social activities (socialization is very important for both of you).
- Encourage the use of long-time skills, like playing the piano, singing, typing, crafts, or speaking a second language.
- Share (and read) the booklet—“Living Well with MCI or Early Dementia” from the Alzheimer’s Association. See a link to this booklet in the [Resource List on pg. 37-39.](#)
- Look for local “dementia friendly” activities, businesses and organizations in your community to stay involved with things you both enjoy doing.
- Consider counseling if you notice an increase in frustration or lack of interest, for either of you.
- Look for connections or support groups that will help your loved one cope with the life changes they are experiencing.
- Stay positive!



Early-Stage Dementia

“My husband’s dementia hasn’t stopped us from living our lives. We take one day at a time and enjoy each other’s company. Best suggestion his doctor gave us!”

- Georgia N.



You may be wondering...

- Are there any medications, treatments, or lifestyle changes that could help the person living with dementia’s memory and thinking?
- How can we help the person living with dementia stay active and connected?
- Should a person living with dementia still be driving?
- Is our legal paperwork in order?



What should you expect in this stage?

What should you expect if your loved one progresses past Mild Cognitive Impairment or early-stage dementia?

The person with dementia will likely have increase in challenges accomplishing some activities. Keep in mind that our amazing brains, even with dementia, will also adapt and come up with other strategies for working through the changes and challenges. Try to recognize the strengths rather than the losses.

They may also:

- Have trouble with time or sequence of events. Visual calendars or alarms can be helpful reminders.
- Forget names of familiar people and things. Remind yourself and others to not make a person with dementia guess what your name is, but offer that information first, even if it feels silly. "Hey John, it's Sally, how are you today?"
- Have decreased performance in work or social situations. Discussing this situation early and coming up with a plan when this begins to happen will hopefully reduce the shock when you must address this. Allowing validation with feelings will help the person living with dementia process the changes that are happening.
- Have trouble multi-tasking. If you are providing reminders and prompts, then try to offer one thing at a time for better success.
- Take more time to process information. Slow down and allow time for a response. This takes practice and does not always come easy, but it will be helpful throughout the journey.
- Write reminders and list them. Try setting up a brain station in one space in your home to keep important reminders or items that are easy to lose. Don't expect recollection of important events, rather, set up a reminder in the phone or call before to prompt.
- Have increased preferences for familiar things. It may be harder to identify newer items or spaces. When replacing things, rearranging spaces, or moving, try to keep everything similar to what was known before. You could also label things together to keep the guessing at a minimum.
- Mild mood and/or personality changes or feel sorrow, suspicion, anger, frustration. Rather than getting defensive, try validating and listening. Talk to a trusted friend or professional about how you are adapting to these changes as well.
- May show increasing indifference to normal courtesies of life. The person living with dementia may not even recognize this is happening and will need others to give them grace and understanding.
- Have trouble driving safely. The conversation about driving should happen early to help you both prepare for alternate ways of transportation and to help lessen the impact of this life changing event. Please reference the [Resource List on pg. 37-39](#).
- Have trouble displaying appropriate self-awareness. This is because the frontotemporal lobe, which recognizes your own self-awareness, may be changing.



At the same time, you may find that the person with dementia has some long-term memory that works 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 have a growing ability to be creative.

You may:

- Feel optimism and/or an early sense of loss and grief.
- Notice a need to provide more reminders and supervision.
- Want to ask for help around the home with housekeeping, errands, laundry, or yard care.
- Be impressed by the person living with dementia's 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, then find a health care professional that will work with you and the person living with dementia together.
- Learn all you can about the disease and tips for communicating supportively with the person living with dementia. See Communication Tips on pg. 31.
- Put safety measures related to driving, falls, wandering, medication use, harmful cleaning products, guns, power tools, etc. in place before they're needed. Find information on safety in the Resource List on pg. 37-39.
- Embrace the good days and prepare yourself for the stormy ones.
- Make your life a no guilt zone.
- Keep up health and wellness appointments for yourself.
- Make efforts to get a good night's sleep every night.
- Seek out support and reassurance: talk with others who have had a similar situation (e.g., early memory loss support group) or call the Alzheimer's and Dementia Resource Service.
- Explore how the person living with dementia wants to live at the end of their lives. Learn about "having the conversation", through the "Conversation Starter Kit for Families of Loved Ones of People with Alzheimer's Disease or other Forms of Dementia." (See Resource List on pg. 37-39).
- Refer to Dementia Friendly Bloomington Website for support with legal and financial issues <http://dfbloomington.org/>

Continued on next page...

What you can do (continued):

To help a person living with dementia:

- Provide “Living with Alzheimer’s: Taking Action Workbook.” Find this in the [Resource List on pg. 37-39](#).
- Go along on medical appointments if the person living with dementia agrees. If they do not want this, then try calling the practitioner ahead of appointments to share concerns.
- Create and stick to simple routines.
- Monitor that any medications are taken properly.
- Encourage them to continue activities of interest.
- Promote the best functioning possible. Get hearing loss and vision checked regularly. Make sure hearing aids and glasses are in good condition and used as needed.
- Resist the urge to step in and do things for them; allow more time and occasional errors.
- Encourage them to attend an early-stage support group and seek out dementia-friendly recreational activities.
- Consider enrolling in a clinical trial or research study on dementia at a university or memory clinic. The person living with dementia may advance our understanding of dementia and help in the effort to develop new treatments.
- When you see behaviors that are “out of character,” do NOT take these personally—recognize it’s the disease.
- Look for ways to modify the person living with dementia’s favorite activities rather than give them up.
- Help family and friends understand how to communicate and interact—if needed you can share what they like to do, how to start a conversation, and the need to avoid correcting and arguing.
- Consider ways to protect yourself and the person with dementia from financial missteps and exploitation. Have a discussion about when you may need to remove a person with dementia’s credit cards (or lower credit limits) and other key wallet documents to keep in a safe place.
- This should also be an early conversation about the potential of fraud by accidental release of information to someone claiming to be trustworthy for the protection of future costs of living and care needs.
- A discussion with your Financial Planner and local Eldercare Attorney can reveal some great ways to help manage future financial care needs.

Services to consider:

- Educational workshops, Alzheimer’s/dementia seminars, E-Learning, and online courses.
- Get connected online—try the Alzheimer’s Navigator, ALZConnected online community, or e-learning modules offered through the Alzheimer’s Association and/or the “Alzheimer’s Reading Room”.
- The Alzheimer’s Association MedicAlert+Safe Return Service—uses a community support network including the police, to locate a person living with dementia in case they wander. Visit www.alz.org/care/dementia-medic-alert-safe-return.asp to learn more. Or, look into locator aids that use active-GPS capability (real-time tracker). Also, consider connecting with your local Project Lifesaver agency: <https://projectlifesaver.org/>
- Consultants who specialize in caregiving or dementia may be available through the Alzheimer and Dementia Resource Services or the Alzheimer’s Association.



You may be thinking,
“I’m tired, afraid, and feel
alone with this.”

“You are not alone! Just take one step
at a time. Contact one or more of the
organizations listed below:

- Area Agency on Aging for your area may be found at <http://www.iaaaa.org/>
- Alzheimer’s Association at 800-272-3900 or www.alzwa.org
- **Dementia Friendly Bloomington** <http://dfbloomington.org/>

Action Steps

The following steps are important at this point:

See Action Steps on pages 10 and 13, and do the following:

- **Obtain a medical assessment** to find out what may be causing any unusual changes or problems. Consider an assessment for yourself if you are overwhelmed. Regular check-ups are necessary for both of you.
- **If a person living with dementia** is still driving and you have concerns, contact <https://iuhealth.org/in-the-community/south-central-region/alzheimers-resource-services>
- **Make sure the person living with dementia** carries their ID, wears MedicAlert+Safe Return jewelry, or is connected to Project Lifesaver.
- **Discuss with the person living with dementia** their wishes for end-of-life care, and document these as decisions are made.
- **Have a family meeting** to discuss what’s happening and next steps, such as ways the family can support the person with memory loss to stay active, healthy, and socially engaged, or help you with decisions and planning about driving or other safety concerns.
- **Make a back-up plan** to be used if something happens to you.
- **Consider Care Coordination or Case Management Services:** Contact your local Area Agency on Aging or the Alzheimer’s and Dementia Resource Service for options.
- **Contact the Alzheimer’s and Dementia Resource Services** for dementia related information, education, and support opportunities.
- **Contact your local Area Agency on Aging** to find out more about local support services.



Mid-Stage Dementia

“The hardest part about this dementia journey for my mom was forgetting familiar faces. We made her a picture board with names and their relationship and that helped her.”

- Francine K.



You may be wondering...

- What can I do to make the home safer?
- What do we do if a person living with dementia 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 a person living with dementia's life more enjoyable?

What should you expect in this stage?

In the middle stage, confusion can become more obvious. A person living with dementia will have increasing needs for care and supervision. They may:

- Have more trouble with memory—such as recalling their own address or personal history. Keeping reminders in wallets or purses, or on the information station in your home may be a helpful solution.
- Have problems organizing, planning, following instructions, and solving problems. Try to label or organize in an easy to find format in the home. You might find it easier to take on more of these tasks as a joint task, assisting the person living with dementia.
- Not recognize familiar people. Reminding friends and family to say their names first as an easy reminder or introducing them yourself as a courtesy. Do not say to the person, “don’t you remember so and so?”. This can cause embarrassment and frustration.
- Forget how to initiate routine tasks or how to complete them, including health and hygiene care. Setting out these items as a visual can be a helpful reminder when you begin to notice these tasks are changing. Education on ways to approach this situation is a good start to decrease your future frustration with this unavoidable change.
- May resist bathing or other personal care. May have episodes of incontinence. Sometimes this can be the hardest part of the changes that occur. If setting out visual cues and reminders are not working here, remember to give grace and understanding that brain changes in this stage could make someone think they have already bathed and smells can go unnoticed, making it difficult to know that an accident has occurred.



- Seek assistance and education on this topic before frustration becomes overwhelming for both of you.
- Have abilities that vary from one day to the next.
- Complain of neglect or blame others when things go wrong.
- Changes or lack of judgment can develop the following behaviors:
 - Trouble sleeping
 - Apathy, passivity
 - Irritability, aggressive talk and actions
 - Clinging (following you around)
 - Repetitive questions
 - Wandering

What should you expect in this stage? (Continued)

- Have delusions (false beliefs) or hallucinations (seeing/hearing things that aren't there). This could be caused by a change in the brain or the inability to remember that something has happened, causing the person living with dementia to sometimes fill in the blanks of moments that they cannot remember. You may hear an unusual story or delusion from them as they try to make sense of the situation. It is often best to go along with it or redirect the conversation.
- Have more problems with balance (increasing the risk for falls). Tunnel vision can be one of the causes for changes in balance. Try to simulate tunnel vision for yourself by placing your hands on your face as if you are looking through binoculars and navigate your home to see what can become an obstacle that needs to be moved or addressed to prevent falls.
- Not be able to contribute to family life in traditional ways. There are always alternatives to adapt how you have done something in the past. Ask their advice and reminisce with them along the way.
- Be increasingly sensitive to caregiver mood & behavior. Even if you do not think your mood has changed, if you see a difference in the person living with dementia, then you may want to take a step back to see if you may be moving too fast with a task or if the mood is being reflected. At the same time, they may be increasingly present in the moment, continue to use their five senses to enjoy the world around them, discover new ways of communicating (nonverbal, touch), and can be quite creative.



You may:

- Feel tired, stressed, lonely, isolated, angry, or irritable. Finding time in your day to have a moment to breathe, pray, read, take a warm shower or bath can be helpful.
- Be wondering if you need assistance or how long you can do this. Be honest with yourself when assessing your needs.
- Notice that other friends and family are wondering how to help and may not actually mind helping with care.

What you can do:

- At this stage, you will need the following kinds of support:
 - Daily relief from care tasks (also known as Respite Care)
 - A network of caring friends and family
 - Time to manage your own self care
- Establish or maintain routines for you & the person living with dementia.
- Try not to mistake their moodiness for rudeness.
- Ask for help with taking care of the home or providing care: housekeeping, errands, yard care, handy person, or in-home assistance for the person living with dementia.
- If you get unwanted opinions or criticisms, then take a step back and recognize that others may be trying to help—see if you can work out a plan for them to assist in some way. Recognize that you are doing the best you can.
- Attend a support group.
- Vent as needed with trusted friends or other caregivers.
- Take safety precautions related to falls, wandering, medication use, harmful cleaning products, guns, power tools, etc.
- Look into support and service options to help maintain current living arrangements, such as in-home care or adult day services.



- If the person living with dementia is still driving, then enlist the help of their health care providers to assess their driving mobility. Call the Alzheimer's Association or the Alzheimer's and Dementia Resource Service for additional ideas. For more information on driving evaluations or to request one, you can visit: www.in.gov/bmv/licenses-permits-ids/driver-ability-program/
- Investigate residential care options in your area in the event that they are needed in your future together. If you are able to make this decision together, both of you will feel better when it might be necessary. These might include assisted living and/or nursing homes. Look into their costs and ways to afford care. Take tours so you'll be prepared if you need to make a decision quickly.

To help the person living with dementia:

- Encourage family and close friends to learn communication tips and techniques—and to help provide activities the person living with dementia still enjoys. Refer them to the Alzheimer’s and Dementia Resource Service (www.alzresourceindiana.org) website or the Alzheimer’s Association 24/7 toll-free Helpline: 800-272-3900.
- Try to provide kindness, understanding, and acceptance.
- Channel their energy—go for regular walks together, and encourage them to help with familiar activities of daily living like vacuuming, sweeping, folding laundry, gardening, etc.
- Simplify tasks and activities; break them into smaller steps—allow more time for the person living with dementia to accomplish them. Try not to worry about how well tasks are done.
- Reminisce—look at old photo albums, a memory book, or old videos. Consider labeling names and giving a short narrative of people in photos or memory books to reduce the frustration of guessing.
- Make sure the person living with dementia gets routine medical care.
- If you notice any SUDDEN changes in behavior, call the physician—this can be a sign of an infection or other medical issue.
- Talk to their doctor about completing a Physician Orders for Scope of Treatment (POST) form (www.in.gov/isdh/25880.html)
- Consider the home environment when looking into fall risk as navigation and vision changes occur with dementia.
- Go to the Alzheimer’s Association’s online “Caregiver Center” to find helpful tips on daily care such as activities providing personal care and managing incontinence. Visit www.alz.org/care to learn more.

Services to consider:

- Education workshops or conferences for caregivers.
- Technology to assist with a variety of tasks—reminders, cameras, chimes to alert if an exterior door opens, etc.
- Explore adult day services in your area which offer the person living with dementia 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.
- Consider the following if you haven’t looked into or used yet:
 - Support Groups
 - Respite Care (in or out of the home)
 - Consultants who specialize in caregiving issues and can assist with behaviors
 - MedicAlert+Safe Return, Project Lifesaver, or GPS locator program
 - Indiana University Speech and Hearing
 - Positive Approach to Care™ techniques

Contact your local Area Agency on Aging and/or Alzheimer’s and Dementia Resource Service to inquire about local education and support services mentioned above. Refer to the [Resource List on pg. 37-38](#).

Want to learn more about residential care options?

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

- Find out more, and what's available in your area at: www.iaaaa.org/ and www.alzresourceindiana.org

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

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

- Area Agency on Aging for your area may be found at 855-567-0252 or www.iaaaa.org/
- Alzheimer's Association at 800-272-3900 or www.alz.org/indiana
- Dementia Friendly Bloomington dfbloomington.org/

Action Steps

The following steps are important at this point:

See Action Steps on pages 10, 13, & 18 and do the following:

- **Consider** a Physical or Occupational Therapy evaluation to maintain or increase independent activities of daily living.
- **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 the person living with dementia and yourself, and any next steps as care needs increase.
- **If help with financing care is needed**, contact your local Area Agency on Aging at www.iaaaa.org/. Meet with an elder law attorney.
- **Complete end-of-life planning**. Discuss and document how the person living with dementia 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

“As a caregiver to someone who has dementia you need to remember to take care of yourself. Find support and rest when you can.”

- Fiona R.



You may be wondering...

- What can we do to promote quality of life?
- What kind of care is best for a person living with dementia?
- What do we want in terms of medical care at the end of a person with dementia’s life?



What should you expect in this stage?

In the late stage, the person living with dementia becomes dependent for many 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. Routine trips, especially after meals, could help reduce accidents. Consider different types of incontinence products and pads for chairs or beds.
- Experience changes in physical abilities including ability to walk, sit, and eventually swallow. Using non-verbal, highly visual cues could be helpful. Learning techniques like Hand Under Hand™ can make these changes more understandable and comfortable for you both.
- Have rigidity, immobility or jerky movements. Take cues from them and move slow when providing care or assisting with transporting.
- Be feeling deep emotions and may be tearful, call out, or yell at times. Hearing a comforting voice, music or familiar sounds of the home can be helpful. Emotions should be validated, if able, by giving the chance to let them know you are listening and present.
- Be vulnerable to infections, especially pneumonia and urinary tract infections. Let the doctor or your care team know if the person seems different than normal, is not eating, or is in pain.

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 the person living with dementia is near.
- Find that friends and family are also experiencing grief.

What you can do:

- Be gentle with yourself and the person living with dementia. Respect yourself for the love and support you have provided for the person living with dementia 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.
- If you haven't already, complete a POST form (www.in.gov/isdh/25880.html).
- Review with the person living with dementia's health care professional any health issues and their related medications that could be reduced or discontinued.
- Consider what kind of emotional support you may want or need during the period near and after death.
- Attend a support group.
- Consider including your closest friends and family in discussions about the end-of-life preferences and plans that have already been made.

To help the person living with dementia:

- 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:

- Palliative care and hospice care
- Support group
- Counseling or other emotional support for yourself
- Spiritual or religious services

You may feel like this, “I’m worn out and I am grieving”

Reach out to others in a similar situation, a care coordinator, a counselor, or anyone from the following agencies:

- Area Agency on Aging for your area may be found at www.iaaaa.org/
- Alzheimer’s Association at 317-575-9620 or www.alz.org/indiana
- Dementia Friendly Bloomington at www.dfbloomington.org/
- Alzheimer’s and Dementia Resource Service at www.alzresourceindiana.org

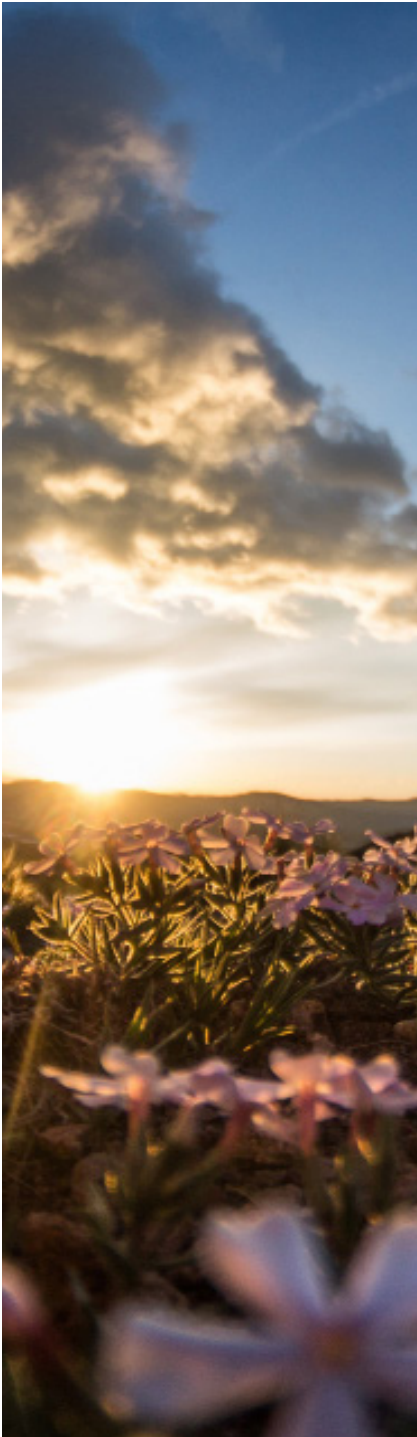


Dementia Quick Reference

10 Warning Signs of Alzheimer's

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

*For more information on "Other Dementias" go to:
www.nia.nih.gov/health/alzheimers/related-dementias*



Early Stage Alzheimer's Disease

- Time or sequence of events may become more difficult to follow.
- May forget names of familiar people and things, however, usually still able to recognize faces of items.
- Changes occur in performance at work or in social situations.
- Becomes more difficult to multi-task.
- Needing more time to process information.
- Increased preferences for familiar things.
- Mild mood and/or personality changes.
- May feel sorrow, suspicion, anger, frustration.
- Changes in driving and wayfinding.
- Decreased safety awareness while driving.

Middle Stage Alzheimer's Disease

- Increasing needs for support care and supervision.
- Experiencing more changes with memory, such as recalling own address or personal history.
- Difficulty organizing, planning, following instructions, and solving problems.
- May begin to have increased difficulty recognizing familiar people, however will have intuition about how an individual has made them feel (safe, scared, welcomed).
- Experiencing more strength than skill.
- Difficulty initiating or completing tasks, needing more prompting to get started during health and hygiene care.
- Abilities that fluctuate from one day to the next.
- May sometimes complain or blame others when things go wrong due to the changes in the ability to understand the situation.
- Changes in safety awareness and judgement may include: trouble sleeping, apathy, passivity, irritability, aggressive talk and actions, clinging (following you around), repetitive questions, wandering, and asking when they last ate.
- Other changes may include: more creativity, openness to others, enjoyment of music, poems and rhythm, the ability to let go of responsibility and become more relaxed in a supportive environment.
- May resist bathing or personal care.
- Could have delusions (false beliefs) to try and make sense of their situation or hallucinations (seeing/hearing things that aren't there).
- Changes in vision and balance (increasing the risk for falls). Binocular Vision usually occurs in this stage.

Late Stage Alzheimer's Disease

- More dependent on personal care activities.
- More difficulty recognizing you or others by name. This does not mean they don't know (or feel) who you are.
- Reflexes are slower and noticeable changes in physical abilities including ability to walk, sit, and eventually swallow
- Increasing difficulty communicating verbally—may use mixed up words, or be speechless, but responds better to tones, music, and rhythm. Using non-verbal (point or show on them or on yourself first before touching) communication in the line of vision can be helpful.
- Incontinence can occur.
- May become rigid with movement and may need to go slow and allow more time to complete tasks.
- May respond best to familiar and comforting experiences/stimuli in the environment
- Increased vulnerability to infections, especially pneumonia and UTIs. Sudden cognitive changes that do not seem normal need to be addressed with the physician.

DISCLAIMER

- These stages are to give an idea of how someone may experience dementia, however every person is different. It is best to focus on abilities retained rather than abilities lost.
- This is not a diagnostic tool but rather a tool to guide you in understanding and preparing for changes that may come.





Communication Tips

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

You can expect that over time, a person living with dementia may struggle to organize their message, lose their train of thought, or speak less often.

What you can do:

- Be present. Let your loved one know you're listening and trying to understand.
- Keep your voice gentle. Hold the person's hand while you talk. Smile, nod, make appropriate eye contact.
- Show respect. Offer your loved one undivided attention, don't multi-task. Include the person living with dementia in conversations, don't talk about them as if they weren't there.
- Avoid distractions. Background noise, like TVs or radios, can compete for attention.
- Position yourself. Be close enough to be heard and seen clearly. Sit or stand at the same level, rather than standing over them.
- Get hearing checked regularly. If the person uses a hearing aid, check that it is working and inserted properly. When speaking, turn your face towards them and make sure your face is in the light so they can easily see your lip movements.

Continued on next page...

What you can do (continued):

- Keep it simple. Use short sentences. Ask one question or offer one instruction at a time. It usually helps to use “positives”—say “Let’s go here” instead of “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 and respond to their emotions. Their tone or body language may provide clues for you.
- Offer comfort. If a person living 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 the person living with dementia 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 living 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 the person living with dementia isn’t trying to be difficult—the disease has changed their brain. Try your best not to take communications and behaviors personally.

It’s also important to know that these are offered as suggestions—we encourage you to forgive yourself when things don’t go as well as you want them to. It can be helpful to talk with others in the same situation to get more ideas and support. The Area Agency on Aging offices and the Alzheimer’s and Dementia Resource Services will know of such opportunities. Reach out today!

Brain Changes

Visual

- Vision can be affected by dementia both physically and in one's ability to "see" someone else's perspective. The visual field, impact of lighting, depth perception, color, and facial recognition are all visual aspects that are usually affected by dementia. Finding out other ways to cue or interact with someone that is not visual can be helpful, such as music. For example, playing music may spark a memory in someone living with dementia or help start up a conversation or interaction.
- For most, vision is the first way of communicating with others and understanding one's surroundings. When vision begins to change, there are ways of relying on other senses to help us continue to communicate. Visual communication can also be strengthened by using contrasting colors for verbal messages or images, and keeping the message short and simple if attempting written communication.
- Make sure to be in the line of sight before attempting to talk or touch someone with these types of brain changes.

Auditory

- Hearing sound is not as much affected by dementia as the ability to know where the sound is coming from or understand/process what you are hearing.
- People living with dementia have difficulty compartmentalizing/blocking out a conversation happening in a different part of the room, so they may begin responding to that conversation as opposed to the one you are having with them. In this situation, it is good to relocate to a quieter room and reduce any distracting sounds such as music in the background
- It is okay to repeat yourself, but if you do, make sure to use the exact same phrase/words since it may take someone living with dementia 10-30 seconds to process what you said.

Touch/Sensory

- Taste and smell are two other senses that are affected by the changing brain. Smell may be impacted by having more difficulty recognizing and interpreting smells. Smell and taste are important to keeping us away from dangerous substances. If this ability is lost, care partners must account for this. Another way that smell can be affected is in one's ability to notice personal hygiene needs. Noticing when it is time to shower, for example, may not always occur.

Brain Changes (continued)

Verbal

- Three language skills are heavily affected by dementia: vocabulary, comprehension, and speech production. Verbal skills that are largely unaffected tend to be social chit chat, recognizing tone, and rhythmic speech. Encouraging the person living with dementia to “tell you more” or “show you” can help with verbal success.
- Try to use supportive body language - ie opening your body when talking with them vs facing directly in front of them.
- Ideally, the message should be kept simple and one topic at a time asked about.

Touch/Sensory

- Sensory changes also occur. Skilled activities, like the ability to zip up a coat, may become more challenging. This is because feeling and manipulating items becomes harder. Being able to adjust to these touch changes is important to do, and care partners should take notice about what activities start becoming frustrating.
- One’s ability to correctly detect touch feelings, temperatures, or levels of pain are also impacted and can be misconstrued.



Brain Health

Movement

- Single most important factor for keeping the brain healthy
- More beneficial than any drug studied to enhance brain function and resiliency to disease
- 150 minutes per week with interval and strength training is recommended
- Ideally 64 minutes each day
- Exercise can turn on “smart genes” which support emotional stability and starve off depression and dementia
- Encouraged to find and make time for exercise each day
- Exercise is not dangerous to do when you are older; it is a lifelong activity
- You don’t get much slower until you reach 70 years of age



Purpose, Learning and Discovery

- Brain resiliency can avoid the symptoms of psychological brain diseases
- Maintaining a sense of purpose gives meaning to your life
- Maintain purpose by continuing to learn, discover, and complete complex tasks
- A strong sense of purpose gives hope, optimism, and a love for life and its experiences
- Increase memory capacity by: Paying attention; Noticing info from all senses; Making info meaningful with imagery; Associating new info with what you already know; Organizing/chunking info into smaller groups



Social Connection

- A meaningful relationship with another person brings love, happiness, and comfort
- Relationships influence cardiovascular, endocrine, and immune systems
- Staying social and interacting with others in meaningful ways can provide a buffer against harmful effects of stress on the brain
- Loneliness has been shown to accelerate cognitive decline in elderly adults



Brain Health (continued)

Sleep and Rest

- Sleep is different from relaxation; we need both to maintain a healthy brain
- Sleep restores the brain and “washes” any waste
- You cannot make up any “lost” sleep
- One poor night’s sleep reduces your ability to wash out beta-amyloid plaques, which are physiological precursors to Alzheimer’s disease
- Aim for an average of 7-8 hours of sleep each night
- It is better to sleep for longer than to take more naps
- Best Practices: Maintain a consistent schedule and avoid long naps; Wake up to early morning light; Get moving



Nourishment

- The key is balance, not avoidance
- Buy organic if you can afford it, especially for foods you cannot peel
- Incorporate seven different colored foods into your nutrition each day
- Eat your largest meal in the morning, a little less at lunch, and your smallest meal for dinner. Otherwise, your body will be digesting all night long
- Some fat is good for you – it is important for myelinating your neurons
- Avoid added sugars and packaged foods
- Best practices: Moderate caloric intake; Eat low glycemic-index carbohydrates (fruits, veggies, and whole grains); Increase intake of omega-fatty-3 acids (salmon, nuts, and seeds); Increase antioxidants



Resources Mentioned in the Document

Organizational Websites

- Alzheimer's Association: www.alz.org/in or 800-272-3900
- Alzheimer's and Dementia Resource Services: www.alzresourceindiana.org
- Dementia Friendly Bloomington at www.dfbloomington.org/
- Indiana's Area Agencies on Aging: <http://www.iaaaa.org/>

Information and Documents

- BMV driver evaluation: www.in.gov/bmv/licenses-permits-ids/driver-ability-program/
- Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Online Guide from the National Institute on Aging: www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide
- Communication: Tips for Successful Communication During All Stages of Alzheimer's Disease: www.alz.org/national/documents/brochure_communication.pdf
- Home Safety for People with Alzheimer's Disease: www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease/introduction
- Living Well with MCI or Early Dementia: www.actonalz.org/pdf/Living-Well.pdf
- Living with Alzheimer's—Taking Action Workbook: www.actonalz.org/pdf/Taking-Action.pdf
- MedicAlert+Safe Return: www.alz.org/care/dementia-medic-alert-safe-return.asp or at 888-413-3768
- Project Lifesaver: <https://projectlifesaver.org/>

Resources for Legal and Advance Care Planning

- Advanced Directive Resource Center: <https://www.in.gov/isdh/25880.htm>
- Conversation Starter Kit For Families and Loved Ones of People with Alzheimer’s Disease or Other Forms of Dementia—To help people with dementia have conversations with their family members about how they want to live at the end of their lives—about the care they want, and the care they don’t want. It is designed to be used in the early stages of dementia. www.theconversationproject.org/wp-content/uploads/2016/05/TCP_StarterKit_Alzheimers.pdf
- Dementia Friendly Bloomington Legal and Financial Planning Committee: <http://dfbloomington.org/legal-and-financial/>
- Community for Justice and Mediation (CJAM): <https://cjamcenter.org/>
- National Academy of Elder Law Attorneys (NAELA): naela.org/findlawyer
- The Indiana POST Program: www.indianapost.org/

Resources on Other Dementias

- Alzheimer’s Disease Education and Referral Center, National Institute on Aging: www.nia.nih.gov/health
- The Association for Frontotemporal Degeneration: www.theaftd.org
- Frontotemporal Disorders: Information for Patients, Families and Caregivers: <https://catalog.ninds.nih.gov/ninds/facet/Health-Topics/term/Frontotemporal-Disorders>
- Lewy Body Dementia Association: www.lbda.org
- Lewy Body Dementia—Information for Patients, Families and Caregivers: <https://catalog.ninds.nih.gov/ninds/facet/Health-Topics/term/Lewy-Body-Dementia>

Go directly to information, resources, and services
in Southern Indiana at: www.dfbloomington.org/

Planning and Service Area 7

Area 7 Agency on Aging & Disabled
 West Central Indiana Economic
 Development District, Inc.
 2800 Poplar St., Suite 9A
 Terre Haute, IN 47803
 812-238-1561 or 800-489-1561
 TDD 800-489-1561
 Fax 812-238-1564

Planning and Service Area 8

CICOA Aging & In-Home Solutions
 8440 Woodfield Crossing Blvd., Ste.
 175
 Indianapolis, IN 46240-4359
 317-254-5465 or 800-432-2422
 Fax 317-254-5494
 TDD 317-254-5497
 www.cicoa.org

Planning and Service Area 10

Area 10 Agency on Aging
 631 W. Edgewood Drive
 Ellettsville, IN 47429
 812-876-3383 or 800-844-1010
 Fax 812-876-9922
 www.area10agency.org
 info@area10agency.org

Planning and Service Area 11

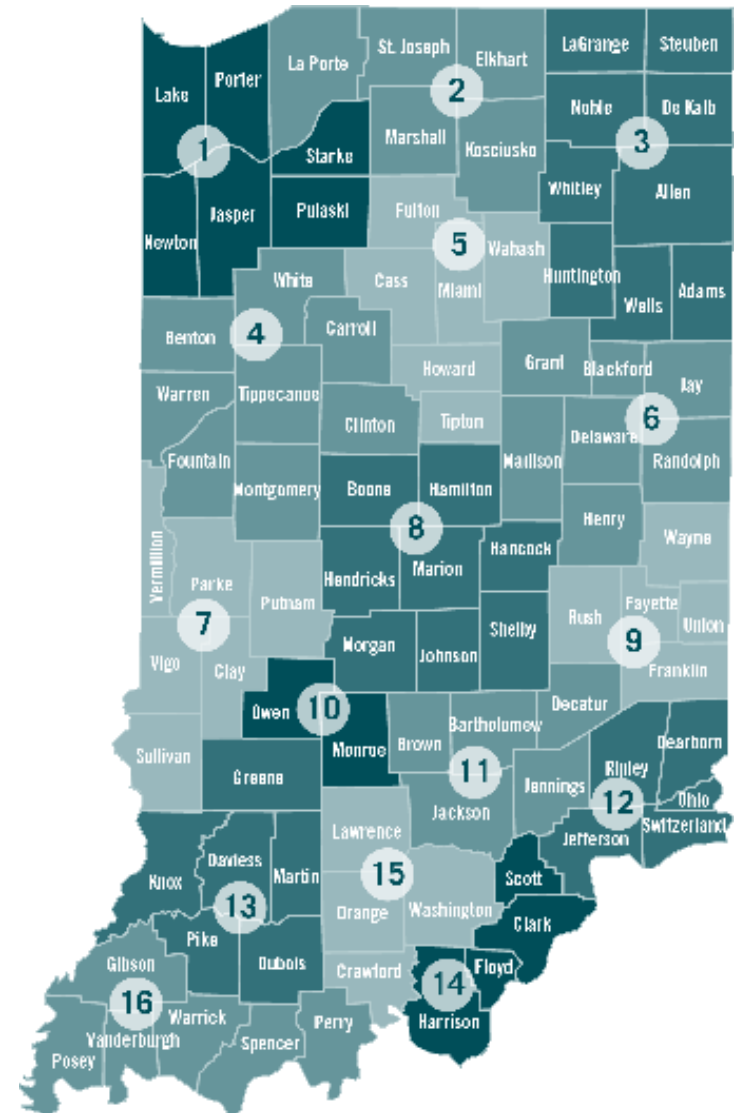
Thrive Alliance
 1531 13th St., Suite G900
 Columbus, IN 47201
 812-372-6918 or 866-644-6407
 Fax 812-372-7864
 www.thrive-alliance.org
 contact@thrive-alliance.org

Planning and Service Area 13

Generations Vincennes University
 Statewide Services
 1019 N. Fourth St.
 Vincennes, IN 47591
 812-888-5880 or 800-742-9002
 Fax 812-888-4566
 www.generationsnetwork.org
 generations@vinu.edu

Planning and Service Area 15

Hoosier Uplands/Area 15 Agency
 on Aging and Disability Services
 521 W. Main St.
 Mitchell, IN 47446
 812-849-4457 or 800-333-2451
 TDD 800-473-3333
 Fax 812-849-4467
 www.hoosieruplands.org
 area15@hoosieruplands.org



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 and the Alzheimer’s and Dementia Resource Service
- Contact your Area Agency on Aging
- Complete health care planning documents/Advance Directives:
 - Health Care Representative or Agents
 - Living Will
 - POST (if deemed appropriate)
- Complete a General Durable Power of Attorney document. In this document, a person appoints an “agent” to assist with financial and related matters.
- Complete an estate plan. The estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- Consider Care Coordination or Case Management Services: “Guides” for the journey who can assist with each step.
- Complete end-of-life planning and document how your loved one wants to live at the end of their life, including medical care wanted or not wanted, comfort measures, and palliative and hospice care.
- Discuss with the person living with dementia the issue of when to discontinue driving. If needed, enlist help of healthcare provider, a professional driving evaluation, or call the Alzheimer’s Association for more ideas.
- Make sure the person living with dementia either carries ID or wears MedicAlert+Safe Return jewelry or Project Lifesaver.
- If help with financing care is needed, contact your local Area Agency on Aging.
- Have family meetings along the way to discuss what’s happening and how to support the person with memory loss and the care partner. Important topics of discussion include:
 - Obtaining an accurate diagnosis for a type of dementia (there are many types of dementia)
 - Discussing safety issues, such as driving and safe medication use;
 - Needing support with financial or legal planning
 - Coordinating care at home; consider a home safety evaluation with your physician
 - Considering safe living situations 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 you.
- Discuss and seek palliative care and hospice care.
- Talk to health care professionals about establishing a Physician’s Order for Scope of Treatment (POST) when appropriate.

Dementia Friendly Bloomington Healthcare and Social Services

Words to Live By:

Volunteer, advocate, caregiver alumnus, and friend Gerald Gonyo lives by “TOODAT” or “Take One Day at A Time.” The expression is inspired by the Dalai Lama who states:

“There are only two days in the year that nothing can be done. One is called yesterday, and the other is called tomorrow, so today is the right day to love, believe, and mostly live.” - Dalai Lama

We are advocating for change in Bloomington and throughout the state so those living with dementia are able to act with autonomy and are given access to resources. Find out more about what we do at www.dfbloomington.org/.

The content of this booklet is derived from “The Dementia Road Map: A Guide for Family and Care Partners” written by the Dementia Action Collaborative from Washington state. A special thanks to Suzanne Allen and IU Corps for connecting us with Nicholas Beer, an Indiana University student who helped create this roadmap.

If you are interested in a paper copy, please contact the Alzheimer’s and Dementia Resource Service at (812) 353-9299.



You can find this publication online at:
www.dfbloomington.org/