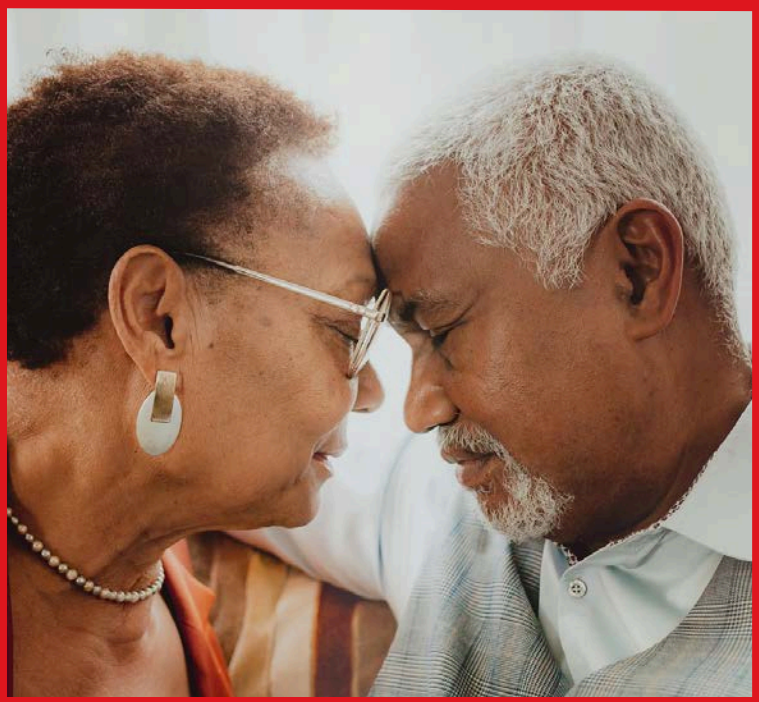
South Carolina
DEPARTMENT
ON AGING

South Carolina Department on Aging Dementia Toolkit



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What is a Dementia Toolkit?

This Dementia Toolkit is an initiative of the South Carolina Department on Aging in response to the growing number of people in our state impacted by Alzheimer's disease or another form of dementia.

This resource aims to help families in South Carolina navigate the dementia journey by providing them with valuable information and resources. For more details on a specific topic, web site links and phone numbers (where possible) have been provided in the resources section at the end of this document.

In an effort to keep content current, we offer an electronic version of this Toolkit, where information is regularly updated. Please note that printed versions may not represent the most current edition.

For more information on the South Carolina Department on Aging and the services provided, go to aging.sc.gov or call 1-800-868-9095.

What is Dementia?

Dementia is not a disease. It is a general term describing loss of memory, reasoning, and other thinking abilities severe enough to interfere with daily life.

Typically, at least one of the following 6 cognitive domains are impacted:

Learning and Memory	Ability to record information and retrieve it when needed
Language	Ability to express thoughts and process received messages
Executive Function	Planning, organizing, problem-solving and decision-making
Complex Attention	Ability to sustain focus and concentration through distractions
Perceptual-Motor	Coordinating senses and motor skills to respond to our environment
Social Cognition	Impulse control, expressing empathy, understanding social cues

What is the difference between dementia and Alzheimer's disease?

These two terms should not be used interchangeably. Think of dementia as an umbrella term describing symptoms. Alzheimer's disease is one of several brain diseases that cause those symptoms. Other causes include vascular dementia, Lewy body dementia, and frontotemporal dementia. It can be helpful to think of the difference this way:

Every case of Alzheimer's disease is dementia.

Not every case of dementia is Alzheimer's disease.

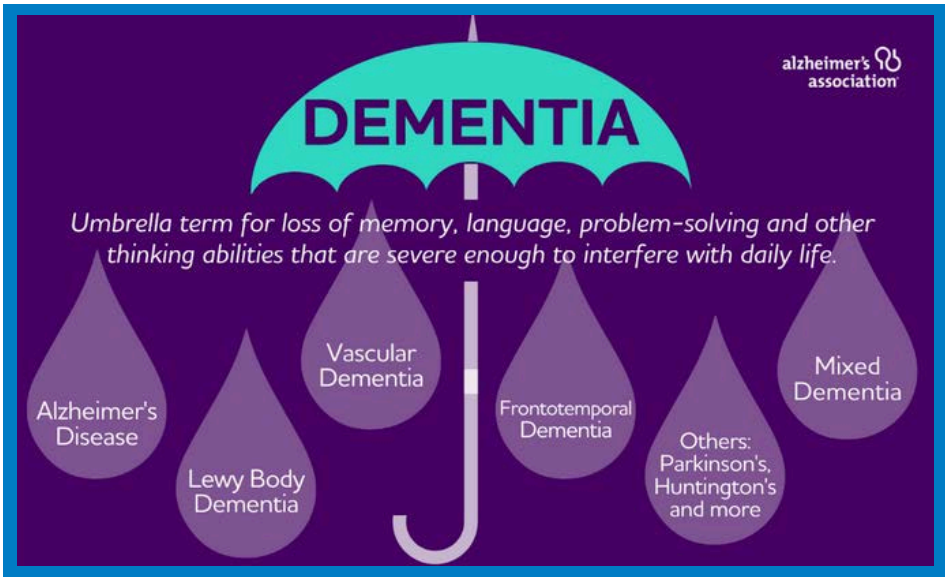


Photo credit: Alzheimer's Association

10 Common Myths About Dementia

Dementia is a normal part of aging.

FALSE (see page 21)

Memory Loss is always the first sign of dementia.

FALSE (see page 8)

There is nothing I can do to minimize my risk for dementia.

FALSE (see page 23)

Symptoms that seem like dementia are never reversible.

FALSE (see page 10)

All people diagnosed with a form of dementia will experience the same symptoms and progression.

FALSE (see page 8)

Dementia only affects people over the age of 65.

FALSE (see page 6 & page 21)

Men are more likely to be diagnosed with dementia than women.

FALSE (see page 22)

There is no benefit from an early diagnosis of dementia because there is no cure.

FALSE (see page 12)

A cognitive assessment is not included in the Medicare Annual Wellness Visit.

FALSE (see page 16 & page 35)

Brain changes associated with dementia start occurring at the same time symptoms appear.

FALSE (see page 8)

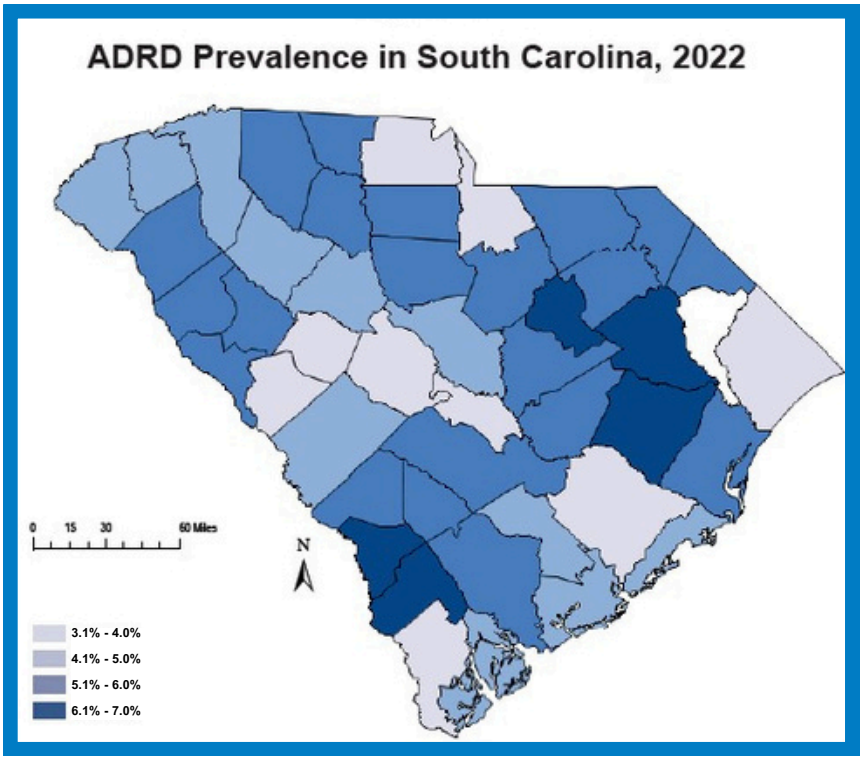
How Common is Dementia?

According to Alzheimer's Disease International, more than 55 million people in the world are living with a form of dementia. In the United States, nearly 7 million people are currently living with Alzheimer's disease specifically.

What about our state of South Carolina?

According to the 2024 South Carolina Alzheimer's Disease Registry maintained by the University of South Carolina Arnold School of Public Health's Office for the Study of Aging:

- 125,538 residents are currently diagnosed with a form of dementia.*
- 11% of SC residents ages 65 or over have been diagnosed with dementia.
- 56% of SC residents ages 85 or over have been diagnosed with dementia.
- 61% of South Carolinians diagnosed are women.
- African Americans ages 65 and over are 32% more likely to have dementia than are non-Hispanic whites.
- Prevalence varies by county:



*These numbers do not include residents who are living with a form of dementia that has not been diagnosed.

WHAT ARE THE MOST COMMON CAUSES OF DEMENTIA?

#1 CAUSE: ALZHEIMER'S DISEASE is an irreversible, progressive brain disease caused by abnormal protein build-up in the brain. This protein build-up occurs within and between nerve cells and disrupts the communication between the cells. This results in the loss of brain cell function, and ultimately cell death. Typically, the first nerve cells damaged are in parts of the brain responsible for memory, language, and decision-making. As damage to the cells continues it will eventually extend to parts of the brain responsible for basic bodily functions like walking and swallowing. It is estimated that Alzheimer's disease is the cause of 60-80% of dementia cases.

#2 CAUSE: VASCULAR DEMENTIA refers to changes in memory, thinking and behavior resulting from conditions (e.g., strokes) that affect blood vessels, reducing the flow of blood and oxygen to certain parts of the brain. Symptoms may be gradual or sudden and then progress over time. Although damage caused by vascular dementia cannot be reversed, some steps may be taken to help limit further damage – for example, managing blood pressure and cholesterol.

#3 CAUSE: DEMENTIA WITH LEWY BODIES ("DLB") occurs when protein deposits called Lewy bodies develop in nerve cells in the regions of the brain involved in thinking, movement, behavior, and mood. Though there can be some similarities with Alzheimer's disease, symptoms unique to DLB may include significant and unpredictable fluctuations in cognition, hallucinations, sleep disturbances, (e.g., acting out dreams) and eventually movement symptoms similar to those in Parkinson's disease.

#4 CAUSE: FRONTOTEMPORAL DEMENTIA ("FTD") results from damage to nerve cells in the frontal and temporal lobes of the brain. There are multiple types of FTD. Behavioral Variant FTD typically involves personality changes and a gradual decline of socially appropriate behavior, judgment, impulse control, and empathy. Primary Progressive Aphasia involves changes in the ability to communicate – to use language to speak, read, write, and understand what others are saying. Movement disorders can result in a loss of balance, unexplained falls, and body stiffness. The majority of FTD cases are diagnosed between the ages of 45-64. FTD is the most common form of dementia for people under the age of 65.

Additional Causes of Dementia:

Creutzfeldt-Jakob disease is a rapidly progressive, and fatal neurodegenerative disorder believed to be caused by misshapen prion proteins.

Huntington's disease is a degenerative brain disorder caused by a defective gene and is typically diagnosed between the ages of 30-50. Symptoms include emotional disturbances, loss of intellectual abilities and uncontrolled movements.

Korsakoff Syndrome is a chronic memory disorder caused by a severe lack of thiamine, often resulting from alcohol abuse.

Normal Pressure Hydrocephalus is a brain disorder where excess cerebrospinal fluid accumulates in the brain's ventricles. The resulting enlargement of these ventricles causes damage to nearby brain tissue.

Posterior Cortical Atrophy involves similar brain changes to Alzheimer's disease, but in a different part of the brain, affecting visual processing and spatial perception.

Mixed dementia occurs when a person is diagnosed with more than one type of dementia.

The following conditions may increase a person's risk for dementia:

Down Syndrome: people diagnosed with Down syndrome are at a significantly increased risk for developing Alzheimer's disease due to an overabundance of Amyloid Precursor Protein (APP) that is also present in Alzheimer's disease.

HIV-associated dementia: when the HIV infection spreads to the brain, it results in encephalopathy (a disease which impairs the brain's function), causing dementia. The greater the spread of the infection in the brain, the worse the dementia symptoms.

Parkinson's disease dementia: up to 80% of people diagnosed with Parkinson's disease will experience significant cognitive decline after a year or more of motor symptoms.

Traumatic Brain Injury (TBI): a condition most often caused by repetitive head trauma. Dementia symptoms may not appear until years after the trauma.

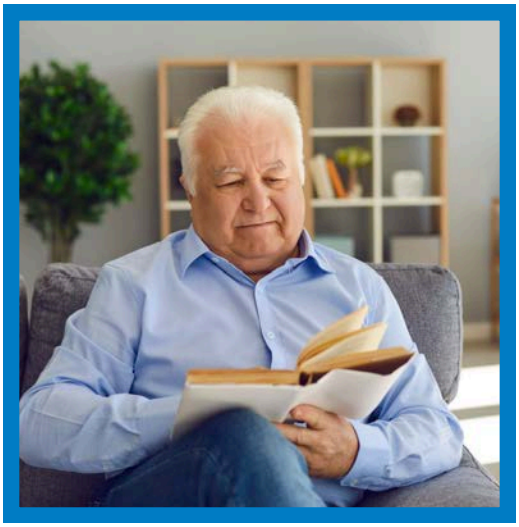
What are Early Signs of Dementia?

The brain changes associated with dementia can begin as many as 20 years prior to the onset of symptoms. Identifying those symptoms early can make a big difference in the quality of care and quality of life for that person.

The figure on page 9 shows the most common early warning signs of dementia.

Important notes:

- Symptoms experienced by a person with dementia can vary based on many factors, including dementia type and stage.
- Each person with dementia is different. Not everyone with dementia will experience the same symptoms and progression.
- Although memory loss is a common first sign of dementia, it is not always the first sign, especially for certain types of dementia.
- Dementia can affect a person as young as their 30s. It is important not to discount these warning signs simply because the person seems too young.



alzheimer's association®

KNOW the 10 SIGNS

EARLY DETECTION MATTERS

Common Early Warning Signs of Dementia

Memory loss that disrupts daily life. 01	• Repeatedly missing appointments • Forgetting something that was just read
Challenges in planning or solving problems 02	• Difficulty managing finances • Issues with following a recipe or filling out a form
Difficulty completing familiar tasks 03	• Trouble completing regular household chores • Challenges with using common devices - e.g., phone, coffee pot
Confused with time or place. 04	• Getting lost coming home from a familiar place • Unaware of the day of the week and not able to recall that later
Trouble understanding visual images or spatial relationships 05	• Feeling for steps with feet to judge their depth • New challenges with reading or writing, especially following lines of text
New problems with words in speaking or writing 06	• Trouble joining or following a conversation • Describing rather than naming a familiar object
Misplacing things and losing the ability to retrace steps 07	• Putting car keys in the refrigerator • Forgetting where car is parked and unable to locate
Decreased or poor judgment 08	• Personal and financial risks that are unusual for them • Paying less attention to hygiene
Withdrawal from work or social activities 09	• Engaging less in hobbies that they once enjoyed • No longer participating in social occasions with friends
Changes in mood or personality 10	• Unusually fearful or suspicious • Making socially inappropriate comments that are not typical

What is Mild Cognitive Impairment?

Mild Cognitive Impairment (MCI) is not dementia, but a stage on the spectrum between normal aging and the first stage of dementia. With MCI, there is a noticeable decline in cognitive ability, but not enough to interfere with the person's daily activities.

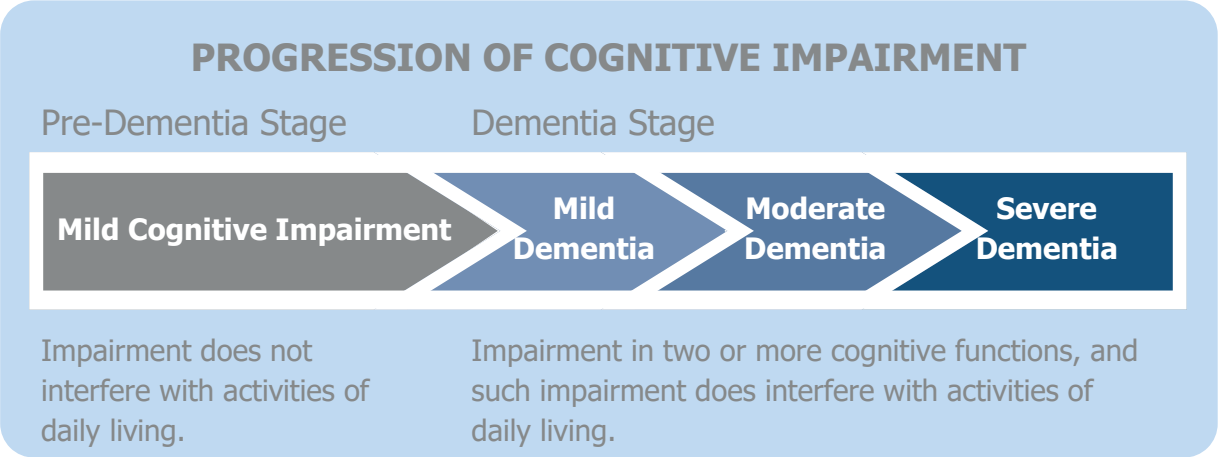


Illustration from the Orange County Vital Brain Program

Not everyone who is diagnosed with MCI will go on to be diagnosed with dementia. In fact, some people with MCI do not experience additional cognitive decline or may even revert to their normal cognition level. Healthy lifestyle decisions can play a big role in limiting this progression (see page 23 for more information).

Are Dementia Symptoms Reversible?

A diagnosis of dementia that is determined to be caused by a brain disease is not currently reversible. However, sometimes symptoms that mimic dementia are caused by medical conditions that may be treatable. Examples include:

- Depression
- Infections (e.g., UTI)
- Medication side effects/interactions
- Hearing loss
- High blood pressure
- Hormonal disorders (e.g., Thyroid)
- Nutritional deficiencies
- Dehydration
- High/low blood sugar levels
- Trauma
- Substance abuse
- Sleep apnea/deprivation

If you are experiencing concerning changes in cognition, the first step is to make an appointment with your doctor to identify and address potentially treatable causes.

Note that the items listed above may also affect someone with dementia and worsen the symptoms.

How is Delirium Different Than Dementia?

Symptoms of delirium are sometimes confused with symptoms of dementia.

Delirium is a sudden and significant change in mental state presenting as confusion, disorientation, and/or a reduced ability to think or remember clearly. It is typically temporary, triggered by a medical condition (e.g., infection, medications, poor nutrition, dehydration) and is usually treatable.

Dementia symptoms progress slowly, over months or years (possible exception: vascular dementia, caused primarily by a stroke) as the result of a brain disease. This progression is not reversible.

A person may have both dementia and delirium. If sudden changes in a person's behavior or orientation occur, it is important to see a doctor for diagnosis and treatment.

Diagnosis

Why is early and accurate diagnosis important?

Although there is not currently a cure for any type of dementia, early and accurate detection and diagnosis can result in significantly better health outcomes. Here's how:

- The symptoms could be caused by a treatable medical condition
- If diagnosed with MCI or early-stage dementia, there are interventions that can help manage symptoms and/or delay progression.
- Treatments are more effective when started early in the disease progression.
- There are some ground-breaking drug therapies that are only approved for use with specific types of dementia, particularly Alzheimer's disease.
- There are cutting-edge biomarker tests (e.g. PET scans, spinal fluid analysis) that can help definitively diagnose the cause of dementia symptoms earlier and more accurately.
- Participation in clinical trials is typically offered to those with MCI or in the early stage of dementia and are usually specific to the type of dementia diagnosed.
- Confirming a diagnosis and determining next steps can relieve stress.
- A person diagnosed early can actively participate in legal and financial decisions.
- Family members and caregivers have time for education and connecting with supportive community resources.

How is dementia diagnosed?

There is no one test that can definitively diagnose any type of dementia. Rather, a comprehensive, holistic approach must be taken.

The figure on page 13 demonstrates the patient journey from symptom awareness to diagnosis.

The first step to address cognitive health is to see your doctor as soon as possible.

JOURNEY TO DEMENTIA DIAGNOSIS

FROM SYMPTOMS TO DIAGNOSIS

EARLY WARNING SIGNS

Subtle cognitive changes emerge, such as memory lapses, difficulty finding words, or trouble managing finances (see page 9 for a list of other possible changes).

Family members or close friends may start noticing behavioral changes.

Individual may dismiss concerns as normal aging.

RECOGNIZING THE NEED FOR MEDICAL EVALUATION

Symptoms are more noticeable and persistent (e.g., repeated forgetfulness, confusion with time/place, difficulty completing familiar tasks).

Family members may encourage a doctor's visit.

Individual may begin avoiding complex tasks or social situations.

PRIMARY CARE EVALUATION

Initial visit with a primary care provider (PCP).

Basic cognitive screenings and medical history review.

Bloodwork and imaging may be ordered to rule out other conditions.

PCP may refer to a neurologist or specialist for further evaluation.

COMPREHENSIVE SPECIALIST ASSESSMENT

Neurological, psychiatric, or geriatric evaluation with in-depth cognitive testing (see page 14 for list of providers).

Brain imaging (MRI, PET Scan, CT) to assess structural changes.

Possible biomarker tests (spinal fluid, blood tests) if available.

Diagnosis confirmation of dementia type and stage.

DIAGNOSIS DISCUSSION AND CARE PLANNING

Healthcare provider discusses the diagnosis and prognosis with the individual and family.

Introduction to dementia care resources (see page 31).

Advance care planning is updated or started.

Lifestyle recommendations for slowing progression (see page 23).

This journey can vary depending on healthcare access, symptom severity, and family involvement. Some individuals may receive a diagnosis faster, while others experience delays due to misdiagnosis or reluctance to seek help.

Early detection allows individuals to access treatment options and support services, and plan ahead, ultimately improving the quality of life for that person and their family members. For more information on the benefits of early and accurate diagnosis, see page 12.

What type of medical practitioner does what?

Primary Care Provider (PCP):
A general health care professional who diagnoses common medical problems. This person is often a medical doctor (MD), Doctor of Osteopathy (DO), physician assistant (PA) or nurse practitioner (NP).

Geriatrician:
A primary care physician who has specialized training in treating older adults.

Neurologist:
A physician who specializes in diagnosing and treating diseases of the nervous system, including the brain and spinal cord.

Geriatric psychiatrist:
A physician trained in the evaluation, diagnosis, and treatment of mental and emotional disorders in older adults, including dementia, sleep disorders, anxiety, and psychoses.

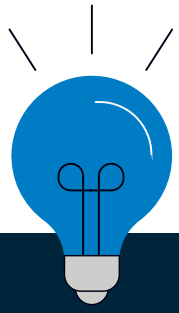
Neuropsychologist:
A psychologist who specializes in the relationship between the brain and behavior. They may evaluate and diagnose individuals with neurocognitive disorders, including brain diseases causing dementia.

What is the difference between a geriatrician and a gerontologist?

- Geriatricians are physicians who specialize in the healthcare of older adults. They address age-related medical conditions, chronic diseases, and the overall health and wellness of older patients.
- Gerontologists are professionals who study the aging process, the challenges older adults face, and the societal impacts of an aging population (e.g., geriatric social workers, public health professionals, academic researchers, or policy analysts).

What can I expect from the first appointment?

- A thorough medical check-up to address treatable causes of symptoms (e.g., hypertension, infection, thyroid issues, etc. See page 10 for details.
- Evaluation of mood and overall mental health to detect depression.
- Questions regarding family history of dementia.
- A cognitive assessment to evaluate memory, language, judgment, visual-spatial ability, and other thinking skills.
- Input from someone close to you to provide their perspective.
- Brain imaging (e.g., MRI, CT, or PET scan).
- Referral to a specialist (e.g., geriatrician, neurologist, or neuropsychologist) which may include additional testing and scans.



Did You Know?

Medicare will help cover the cost of this visit!

If a patient covered by Medicare shows signs of cognitive impairment during a routine visit, Medicare will cover a separate visit to thoroughly assess cognitive function and to develop a care plan. Financial concerns should not be a factor in obtaining a diagnosis.

How Can I Prepare for this Appointment?

Before your appointment to discuss your cognitive concerns with your physician, it is advisable to be prepared with the following:

- Ask what to expect from the appointment.
- Determine, if possible, any history of dementia in your family.
- Identify other family medical history concerns, including mental health, cardiovascular, blood sugar, and alcohol/drug addiction.
- Your own medical history - this information can help your doctor determine certain dementia risk factors.
- A list of your prescribed and over-the-counter medications. Timeline for when you started or stopped taking medications.
- Detailed examples that demonstrate your cognitive concerns. Be sure to include what happens as well as when and where.
- Ask one or two close family members/friends for honest insight. Sometimes, those who spend a lot of time with us notice changes before we do.
- Bring one of those trusted family members/friends to the appointment.
- Be honest - there is no benefit to omitting information that could be important for an accurate diagnosis and treatment plan.
- Come prepared with questions (see resources section for suggestions).

If a dementia diagnosis is confirmed, what are some important questions to ask?

- **What type of dementia is it? ("dementia" should rarely be the final diagnosis.) This can make a difference for treatment and care plans.**
- **How did the doctor(s) arrive at this diagnosis?**
- **Approximately what stage are we in the progression of the disease that is causing dementia?**
- **What are next steps?**
  - **Referral to a specialist (e.g., geriatrician, neurologist) if not already seeing one**
  - **Additional testing such as a PET scan and other biomarkers that can help confirm the type of dementia?**
- **What treatment options are available?**
  - **Lifestyle changes?**
  - **Drug therapies?**
- **How will the effectiveness of these treatments be assessed?**
- **What are reasonable goals for me now and in the future?**
- **Given the diagnosis, is it safe for me to drive?**
- **Are there any other safety considerations?**
- **Can you recommend any clinical trials?**

What Treatments are Available?

Although there is currently no cure for any type of dementia, there are treatment options that can help. Several drugs have been approved by the Federal Drug Administration (FDA). We will provide a general overview here.

There are generally 2 types of drugs that have been approved by the FDA:

1. **Those that treat cognitive symptoms:**
    - While these medications do not stop the damage the disease causes to the brain, they may help lessen or stabilize symptoms for a limited time.
    - Examples include Aricept, Exelon, Razadyne and Namenda.

2. **Those that may modify disease progression:**
    - Two new drugs have been approved by the FDA for Alzheimer's disease: Leqembi (Lecanemab) and Kisunla (Donanemab).
    - These are different from other drug treatments in that they address the potential **cause** rather than just the symptoms of Alzheimer's disease. They use a synthetic protein to reverse amyloid plaques, which are a hallmark of Alzheimer's disease.
    - These are administered through IV and are appropriate in the early stage of Alzheimer's disease or with a diagnosis of MCI due to Alzheimer's disease.

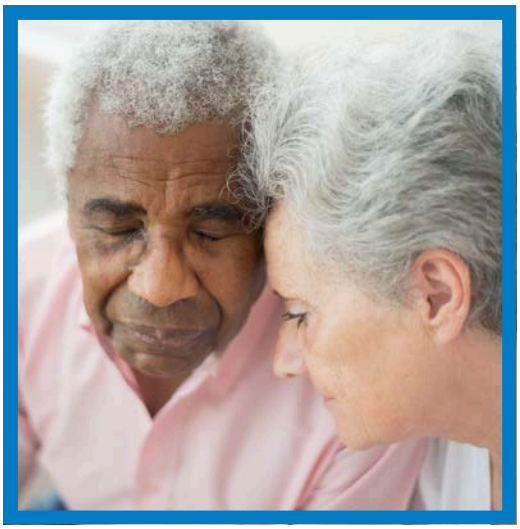
Treating non-cognitive symptoms:

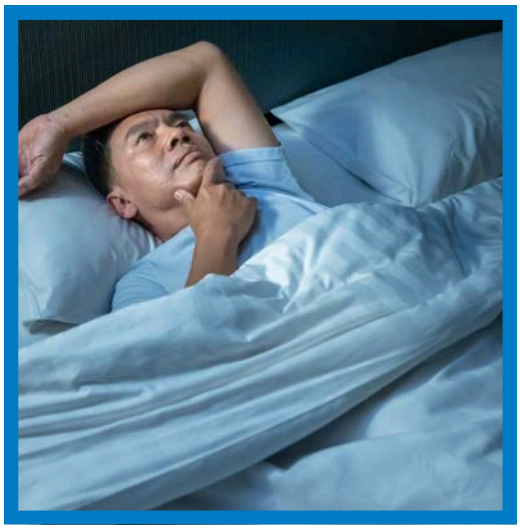
There are medications approved by the FDA to treat non-cognitive symptoms associated with dementia, such as mood disorders, insomnia, and hallucinations. Some of these medications are not specifically approved for use in people with dementia and may pose a higher risk to those with certain types of dementia.

Benzodiazapines (e.g., Valium, Xanax, Ativan) are not typically recommended by the medical community or are only recommended for the lowest dosage for people diagnosed with dementia due to the potential side effects for this population.

A list of common medications prescribed to people diagnosed with dementia and the purpose of each is provided in the figure on page 20.

A word of caution: As with all medications, risks and benefits must be weighed. Not all of these medications are appropriate for everybody. Dementia type, stage and the individual's medical history are all important factors to consider. Your doctor is the best resource to determine which medication may be best for you or your loved one.





Common Medications Prescribed to Persons Living with Dementia

Purpose	Name	Brand name	Type	Approved by FDA to treat:
Treat cognitive symptoms	Donepezil	Aricept	Cholinesterase inhibitor	All stages of Alzheimer's disease
	Rivastigmine	Exelon	Cholinesterase inhibitor	Mild to moderate stages of Alzheimer's and Parkinson's diseases
	Galantamine	Razadyne	Cholinesterase inhibitor	Mild to moderate Alzheimer's disease
	Memantine	Namenda	Glutamate regulator	Moderate to severe confusion related to Alzheimer's disease
	Donepezil + Memantine	Namzeric	Cholinesterase inhibitor + glutamate regulator	Moderate to severe confusion related to Alzheimer's disease
Disease modifying	Lecanemab	Leqembi	Monoclonal antibody	Mild Alzheimer's disease and MCI (administered via IV)
	Donanemab	Kisunla	Monoclonal antibody	Mild Alzheimer's disease and MCI (administered via IV)
Treat non-cognitive symptoms	Brexpiprazole	Rexulti	Atypical antipsychotic	Agitation associated with dementia (FDA-approved for people with dementia)
	Pimavanserin	Nuplazid	Atypical antipsychotic	Approved for Parkinson's disease psychosis
	Aripiprazole	Abilify	Atypical antipsychotic	Helps to regulate mood, behaviors, thoughts*
	Risperidone	Risperdal	Atypical antipsychotic	Helps to regulate mood, behaviors, thoughts*
	Quetiapine	Seroquel	Atypical antipsychotic	Helps to regulate mood, behaviors, thoughts*
	Olanzapine	Zyprexa	Atypical antipsychotic	Helps to regulate mood, behavior, thoughts*
	Clozapine	Clozaril	Atypical antipsychotic	Helps to regulate mood, behavior, thoughts*
	Haloperidol	Haldol	Typical antipsychotic	Helps to regulate mood, behavior, thoughts*
	Thiothixene	Navane	Typical antipsychotic	Helps treat hallucinations/delusions*
	Trazodone	Desyrel	Antidepressant	Also used to treat insomnia

* Not FDA-approved for people with dementia

Sources:
Alzheimer's Association. (2019). Medications for Memory. Alzheimer's Association. https://www.alz.org/alzheimers-dementia/treatments/medications-for-memory
Kernisan, Leslie. "5 Types of Medication to Treat Difficult Alzheimer's Behaviors." Better Health While Aging, 20 Sept. 2018, betterhealthwhileaging.net/medications-to-treat-difficult-alzheimers-behaviors/.

What is my risk for dementia?

According to the National Institute of Health, most diseases that result in dementia do not have one specific cause. Rather, most have multiple causes which often include a combination of age-related changes in the brain along with genetic, environmental and lifestyle factors. The importance of any one of these factors in increasing or decreasing the risk of dementia may differ from person to person.

- **Increasing Age:** The greatest known risk factor for dementia is increasing age. An important clarification: although risk for dementia increases with advancing age, dementia is not a normal part of the aging process. Many people age into their 80s and 90s without any form of dementia.

  Most people with Alzheimer's disease (the most common form of dementia) are age 65 and older. After age 65, the risk doubles every 5 years. About one-third of people ages 85 and older have Alzheimer's disease (U.S. Alzheimer's Association).

- **Family History:** Family history is not necessary for an individual to develop Alzheimer's disease. However, research shows that those who have a parent or sibling with Alzheimer's disease are more likely to develop the disease. The risk increases if more than one family member has the illness. This is also the case with most other types of dementia.

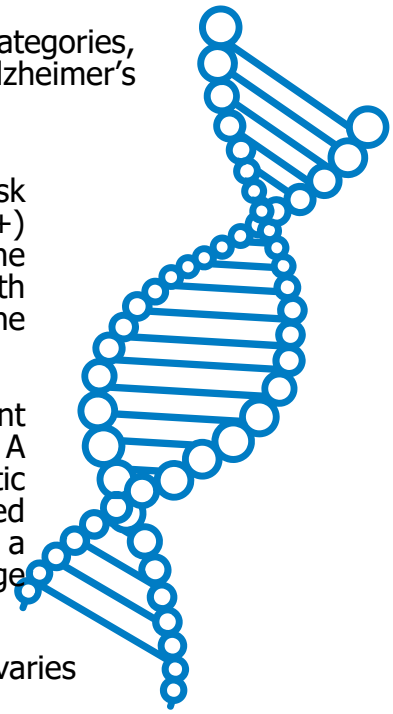
- **Genetics:** Most types of dementia do not have a single genetic cause. Instead, risk can be influenced by multiple genes, in combination with lifestyle and environmental factors.
  - Two categories of genes influence whether a person develops a disease:
    - **Risk Genes** increase the likelihood of getting the disease
    - **Deterministic Genes** directly cause the disease

      Alzheimer's genes have been found in both categories, however, it is estimated that less than 1% of Alzheimer's cases are caused by deterministic genes.

  - Late-Onset Alzheimer's disease: The most common risk gene found in late-onset (symptoms begin at age 65+) is called APOE e4. Inheriting the APOE e4 gene from one parent increases your risk. Inheriting the gene from both parents further increases risk. Approximately 2% of the US Population has two copies of APOE e4.

  - Young-Onset Alzheimer's disease (symptoms present prior to age 65) is more closely linked to genetics. A person whose biological parent carries the rare genetic variant has a 50/50 chance of inheriting that altered version of the gene. If they do inherit it, there is a likelihood of developing Alzheimer's disease before age 65.

  - The influence of genes in other forms of dementia varies widely.



- **Gender, Race, and Ethnicity**: According to the Alzheimer's Association's 2024 Facts and Figures Report:
  - 2/3 of people diagnosed with dementia in the United States are women.
  - Black older adults are twice as likely as White older adults to have Alzheimer's disease or another form of dementia.
  - Hispanic older adults are about one and one-half times as likely as their White counterparts to have dementia.
- **Down Syndrome**: People with Down syndrome have an increased risk of developing Alzheimer's disease due to an overabundance of Amyloid Precursor Protein (APP), also found in Alzheimer's disease. The Down Syndrome Society estimates that 30% of people with Down Syndrome in their 50s and 50% of those in their 60s have Alzheimer's disease.

Is there Anything I Can Do to Lower My Risk?

Yes!! A 2024 study update by the Lancet Commission found that **45% of dementia risk is within our control.** The healthier we are, the less influence factors like age and genetics can have on our risk. See the figure on page 25 for more details.

What steps can we take to lower our risk of dementia?

Get Moving:

According to the CDC, cognitive decline is almost twice as common among adults who are inactive compared to those who are active. This does not mean you need a ton of time or expensive equipment. Just keep moving! Find activities that you enjoy:

- Walk your dog (or offer to walk your neighbor's dog!)
- Sign up for a fun class like dance, yoga, water aerobics or tai chi
- Try a new sport such as golf or pickleball
- Take a nature hike
- Tend a vegetable garden
- Do regular house chores
- Use the stairs instead of the elevator

Feed your brain like you do your heart:

Research has shown a proven connection between heart health and brain health so eating a healthy diet can double your benefits! Crash diets are often not the best long-term choice. Find a sustainable nutrition plan, preferably low in salt, sugar and processed foods. It is okay to splurge sometimes - making healthy decisions most of the time will go a long way.

Socially connect:

A 2022 Johns Hopkins study found that socially isolated older adults have a 27% higher chance of developing dementia than older adults who were not socially isolated. Make a regular lunch date with friends, attend a game night, have coffee with a neighbor, Zoom with family far away.

Check your hearing:

A Johns Hopkins study that tracked 639 adults for nearly 12 years, found that mild hearing loss doubled dementia risk. Moderate loss tripled risk, and people with a severe hearing impairment were five times more likely to develop dementia. Further, studies have shown that the regular use of hearing aids can significantly reduce that risk.

Treat vision loss:

The Lancet Commission found a 47% increase in risk for dementia in adults who have untreated vision loss. They also found that diabetic retinopathy had significant associations with dementia risk.

Manage chronic health conditions:

Unmanaged chronic health conditions such as hypertension, high cholesterol, diabetes, obesity, smoking, depression, and excessive alcohol consumption are all associated with a higher risk of dementia.

Learn new things:

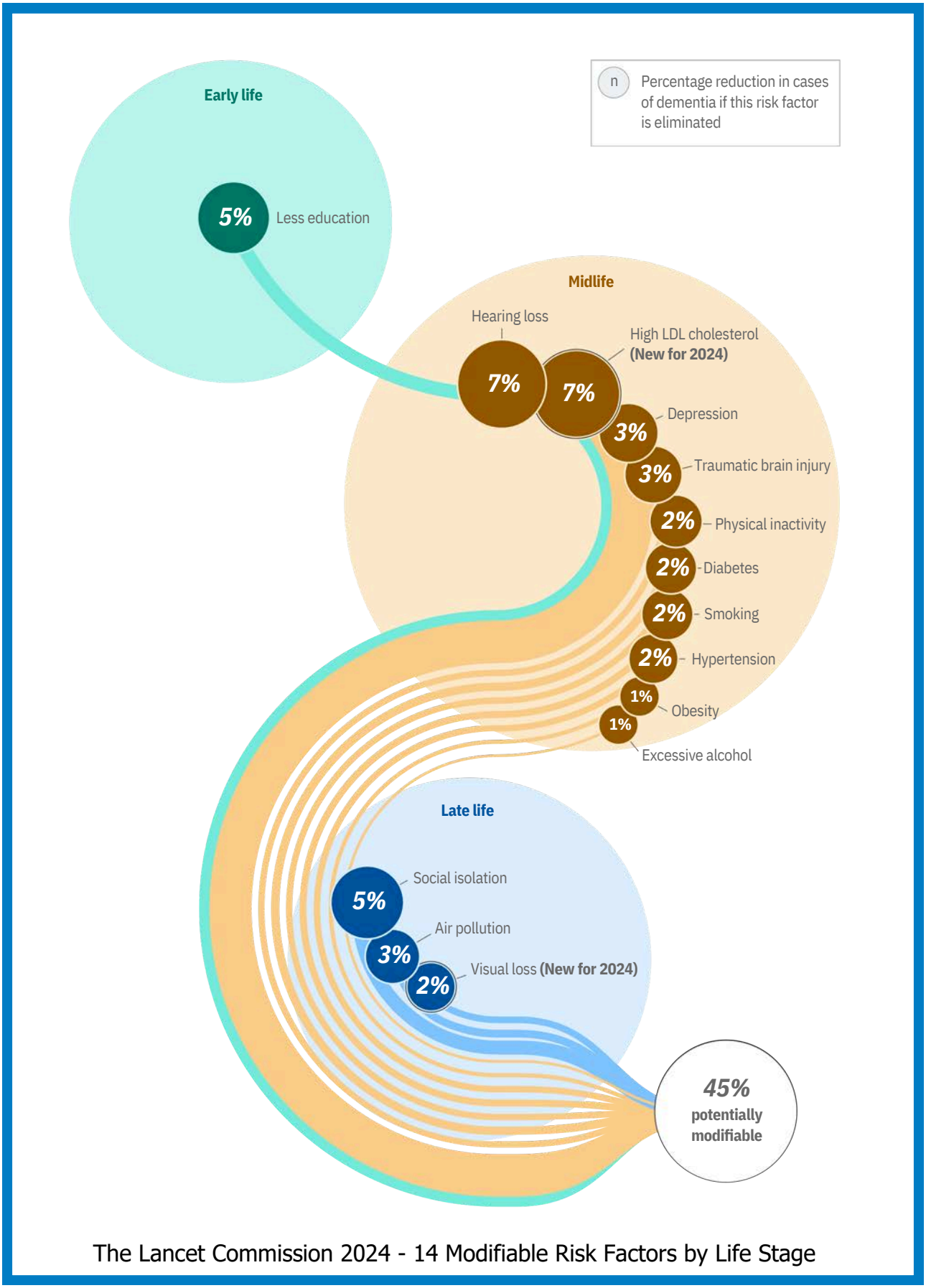
Studies have found that obtaining formal education early in life can reduce dementia risk. More recent studies, such as that from the Lancet Commission, have also found that learning new things later in life - like a hobby or language - can also help reduce that risk.

Protect your noggin:

Research has shown that the effects of head injuries can be long-lasting. A 2021 University of Pennsylvania study found that a history of a single prior head injury is associated with a 1.25 times increased risk of dementia, and over 2 times increased risk of dementia for 2 or more prior head injuries when compared to individuals with no history of head injury. Wear your helmet and seat belt!

Restorative sleep:

A long-term Harvard Medical School study followed 2,800 people aged 65 and older. Researchers found that individuals who slept under 5 hours per night were twice as likely to develop dementia compared to those who slept 6-8 hours per night. The exact reason for this is still being researched, but recent findings suggest that sleep plays a role in removing waste in the brain that builds up while we are awake.



The Lancet Commission 2024 - 14 Modifiable Risk Factors by Life Stage

What Are Next Steps After Diagnosis?

Keep living your life: Receiving a diagnosis of any type of dementia can be overwhelming. However, it is possible for the person diagnosed to live well by taking control of their health and wellness, and focusing energy on aspects of their life that are most meaningful to them. This is especially the case if diagnosed in the early stage. As long as it is safe, continue with activities you have always enjoyed, and modify as needed. Caregivers and family members are encouraged to support independence.

Get educated: To determine an appropriate treatment and care plan, it is important to know the type of dementia diagnosed, and the approximate stage of dementia.

The next step is to learn as much as you can about the diagnosis, available treatments, and resources to support both the person diagnosed and their caregiver(s) long term.

Establish care plans:

1. **For the Person Diagnosed:**
   - **Medical/Treatment**
     - Recommended lifestyle guidelines (see page 23)
     - Learn what drug therapies are available. Identify available clinical trials in which to participate (see page 40)
     - Review the list of medications you are on with your doctor and caregiver to make sure you understand what you are taking and its purpose.
     - Confirm what routine follow-up visits will be needed and with what medical professionals
     - Document all of the above in a central location. Keep a log of questions/concerns to reference at your next appointment.

   - **Social/Emotional**
     - Find a support group (see page 38)
     - Focus on what you CAN do and do it!
     - Provide self-care in whatever form makes sense for you (go for a walk, watch a funny show, have lunch with friends, meditate...)

   - **Legal:** Contrary to what many people think, the biggest reason for getting our legal and financial affairs in order is not to prepare for our death, but to prepare to live well and comfortably as we age. Some of the documents recommended include:
     - **Advance Directives**: a written record of your wishes regarding your health care that is created long before there is a medical crisis. Advance directives go into effect only when you are not capable of making decisions for yourself. Examples include:
       - Healthcare Proxy or Healthcare Power of Attorney: a written document in which one person (the "principal") authorizes another trusted person (the "agent") to make medical decisions on the behalf of the principal should that person become unable to make their own decisions. Although witness signatures are required, a healthcare power of attorney does not require notarization.
       - The Living Will: a legal document that tells others what your personal choices are about end-of-life medical treatment. It lays out the procedures or medications you want - or don't want - to prolong your life if you can't talk with the doctors yourself.

Next Steps (Continued).

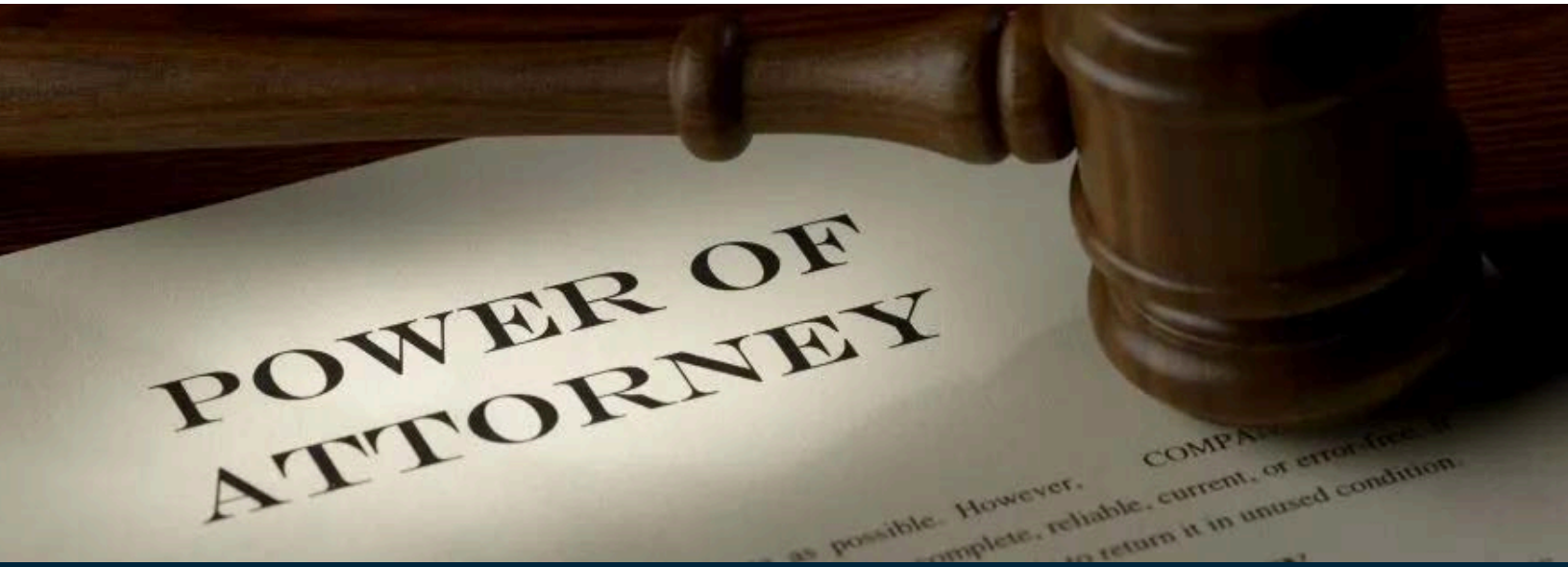
- Five Wishes: a comprehensive document designed to make end-of-life planning simpler and more personal while fostering important conversations with family and caregivers. It helps individuals outline their healthcare and personal wishes in five areas: the person to make decisions, desired medical treatment, comfort preferences, how they wish to be treated, and messages for loved ones.

- **Power of Attorney** (financial): a written document in which one person (the "principal") authorizes another person (the "agent") to act on their behalf under specific circumstances. Power may be broad or limited to specific decisions in the principal's best interests.

  This can be a useful tool if/when the principal is unable to conduct their own business due to illness, disability, or lack of transportation. Note that the power of attorney must be notarized and filed with the county clerk's office. It terminates upon the death of the principal.

- **Will**: a legal document that coordinates the distribution of your assets after death and can appoint guardians for minor children. Your will may designate a person of your choice to act as a personal representative of your estate.

- **Financial**
  - Take time to consider what your long-term living plan is. This may not look the same for everyone. Some may prefer a long-term care community setting and others may want to remain at home. Understanding your options, identifying your preferences, and planning finances accordingly are all critical.
  - Meet with a banking professional to review accounts to ensure the appropriate people have access to those accounts.
  - If there is a safe deposit box, be sure the appropriate people have access to it, especially if it contains important documents.
  - Ensure current beneficiaries are set up on all investment accounts.
  - Talk with the agent of your Power of Attorney to make sure they understand your plan.



Next Steps (Continued).

2. **For the care partner(s):** Although caregiving can be rewarding, the ongoing demands of taking care of someone else can strain even the most resilient people. It can be overwhelming to juggle caring for your loved one in addition to family and work obligations. Without proper planning and support, burnout often results. That is why it is critical for caregivers to have a care plan for themselves as well as for the person with dementia. So, how do we do that?

   - **<u>Find a Support Group</u>**:

     Support groups can be helpful for both the person diagnosed and their care partners to share their journeys with people who understand, learn coping skills, discover effective resources, and how to find joy.

   - **<u>Build Your Care Team</u>**:

     A strong support team is important to help you and the person you are caring for. Who should be on this team? Think broadly when identifying people who could be helpers:

     - Family Members (Near and Far)
     - Friends (Near and Far)
     - Neighbors
     - Faith-Based Organizations
     - Healthcare Workers (i.e. PCP, specialist, social workers)
     - Government Agencies (i.e. Social Security , VA)

     Create your team now rather than scrambling for help when a crisis occurs.

The figure below shares some examples of key people who may play a supportive role.

How can I engage people to help?

It can be uncomfortable asking for or accepting help from others. Often, people want to help but may not know what you need. Here are some tips:

- Make a list - record all current household, family and caregiver tasks. This can be useful to reference when people offer to help. You can provide some options for them to choose from that make the most sense for them.
- Keep in mind that there are plenty of tasks that people can help with that don't involve direct care but still relieve some stress.
- Work to people's strengths, distance, and available time. For example, a trusted out-of-town family member may be a good option to help with online banking tasks. A neighbor may help mow the lawn, while a book club may coordinate to provide dinner once a week.
- Create and maintain a daily care plan for those providing direct care to your loved one. This will make it easier for someone else to step in to provide quality care and support specific to your loved one. This, in turn, allows you to take breaks while ensuring consistent care from others.

- Thank your support team members. People appreciate being appreciated! And that will increase the likelihood of their continued help. This can be as simple as a handwritten note or a quick text.

Prioritize self-care in your plan:

To be the best care partner possible, it is first important to take care of YOU. Incorporate self-care into your schedule. Examples include going to your own medical appointments, a worship service, taking a walk, lunch with friends or taking a nap. Whatever brings you health, happiness and balance is considered self-care. Coordinating with members of your caregiver team and engaging **respite care** both play a supporting role.

What is respite?

Respite is a temporary break for primary caregivers, giving them time to rest, relax and recharge. Respite care can take place in the home, in a healthcare facility or at an adult day center. South Carolina provides a Family Caregiver Support Program for caregivers in our state, which includes respite care. Contact your area agency on aging (see page 31) to get connected to respite care and other supportive services for family caregivers.

What Resources Are Available for Support?

South Carolina Department on Aging

The South Carolina Department on Aging (SCDOA) enhances the quality of life for older adults in South Carolina. The SCDOA works with 10 regional Area Agencies on Aging (AAA) and a network of local providers to develop and manage services that help older adults remain independent in their homes and communities.

Each AAA has a dedicated Family Caregiver Advocate who can help connect people diagnosed with dementia and their care partners with supportive services and education. Additional services offered by the AAA offices include adult advocacy, nutrition, in-home care, insurance counseling and transportation, among others.

Area Agencies on Aging

Region I: Appalachian Telephone: 864-242-9733 Counties Served: Anderson, Cherokee, Greenville, Oconee, Pickens and Spartanburg	**Region II: Upper Savannah** Telephone: 1-800-922-7729 Counties Served: Abbeville, Edgefield, Greenwood, Laurens, McCormick and Saluda
Region III: Catawba Telephone: 1-800-662-8330 Counties Served: Chester, Lancaster, York and Union	**Region IV: Central Midlands** Telephone: 1-866-394-4166 Counties Served: Fairfield, Lexington, Newberry, Richland
Region V: Lower Savannah Telephone: 803-649-7981 Counties Served: Aiken, Allendale, Bamberg, Barnwell, Calhoun and Orangeburg	**Region VI: Santee Lynches** Telephone: 803-775-7381 Counties Served: Clarendon, Kershaw, Lee and Sumter
Region VII: Pee Dee Telephone: 843-383-8632 Counties Served: Chesterfield, Darlington, Dillon, Florence, Marion, and Marlboro	**Region VIII: Waccamaw** Telephone: 843-546-8502 Counties Served: Georgetown, Horry, and Williamsburg
Region IX: Trident Telephone: 843-554-2275 Counties Served: Berkeley, Charleston, and Dorchester	**Region X: Lowcountry** Telephone: 1-877-846-8148 Counties Served: Beaufort, Colleton, Hampton, and Jasper

GetCareSC.com

For more information, including a guide to services and a provider look-up tool, go to www.getcaresc.com or call 1-800-734-9900.

Dementia Care Specialist Program
The SCDOA created the Dementia Care Specialist Program in 2022. If you need help navigating a suspicion or diagnosis of dementia, caregiver assistance or getting connected to support resources, call 1-800-868-9095 or email dementia@aging.sc.gov.

ALZHEIMER'S ASSOCIATION®

In addition to leading the charge in dementia research and policy, many educational programs and support services are offered through the Alzheimer's Association. Several of these are referenced in this resource section or you can go to www.alz.org/sc.

Also provided is a 24/7 helpline. Through this free service, trained staff offer confidential support and information to people living with dementia, their caregivers and family members:

24/7 Helpline: 800-272-3900

Dial 711 to connect with a TRS operator

The Alzheimer's Association's South Carolina Chapter has offices in the Midlands, Upstate and Lowcountry. To get connected, call 800-272-3900.

Education

The **Dementia Care Specialist Program** provides dementia education webinars that are free and open to anyone in the public:

- **Dementia 101: The Basics** – this webinar is provided the first Wednesday of each month from 1-2pm. Topics include dementia types, stages, warning signs, risk factors, diagnosis, treatment options, and support resources available.

- **Dementia 201: Positive Interactions** – a webinar providing practical communication and problem-solving strategies for caregivers, family members and supporters of a person living with dementia.

To register for either of these courses, scan the QR code, call 1-800-868-9095 or email dementia@aging.sc.gov.

These and many other programs can also be presented in the community. To request a speaker at an upcoming event to present about dementia or other aging-related topics, go to https://aging.sc.gov/about, click "speaker request form" or call 1-800-734-9900.

Alzheimer's Association Training and Education Center

1-800-272-3900

National Alzheimer's and Dementia Resource Center (NADRC)

Explaining Alzheimer's disease - videos:

What is Alzheimer's? (3-minute video)

NIA - How Alzheimer's Changes the Brain (4-minute video)

Resources on Causes of Dementia

The Alzheimer's Association Dementia Types

Vascular Dementia

1-800-AHA-USA-1

Lewy Body Dementia

1-800-539-9767

Frontotemporal Dementia

1-866-507-7222

Parkinson's Disease Dementia

1-770-450-0792

Creutzfeldt-Jakob Disease

1-800-659-1991

Posterior Cortical Atrophy

Huntington's Disease

1-800-345-HDSA (4372)

Normal Pressure Hydrocephalus

1-888-598-3789

Wernicke-Korsakoff Syndrome

1-888-696-4222

Dementia from Traumatic Brain Injury (TBI)

1-703-761-0750

Alzheimer's Disease and Down Syndrome

1-800-221-4602

Living Well with Dementia

National Council of Dementia Minds
(organization founded and governed by people living with dementia)

Alzheimer's Association - Living Well Online Resources

Conversations to Remember
(a virtual, intergenerational connection initiative)

1-862-243-5331

NIA - Tips for Living Alone with Early-Stage Dementia

1-800-222-2225

Younger Onset Resources

Alzheimer's Association - Younger-Onset Alzheimer's Disease

Mayo Clinic - Young Onset Alzheimer's Disease

Rare Dementia Support

Lorenzo's House

773-636-9192

Without Warning

Diagnosis

National Institute on Aging – How is Alzheimer's disease diagnosed?

1-800-222-2225

Alzheimer's Association – Medical Tests for Diagnosing Dementia

Early Detection and Diagnosis

Diagnosing Mild Cognitive Impairment

Mayo Clinic - Mild Cognitive Impairment

Cognitive Assessment - Medicare Annual Wellness Visit

If a patient shows signs of cognitive impairment during a routine visit, Medicare covers a separate visit to thoroughly assess the patient's cognitive function and to develop a care plan.

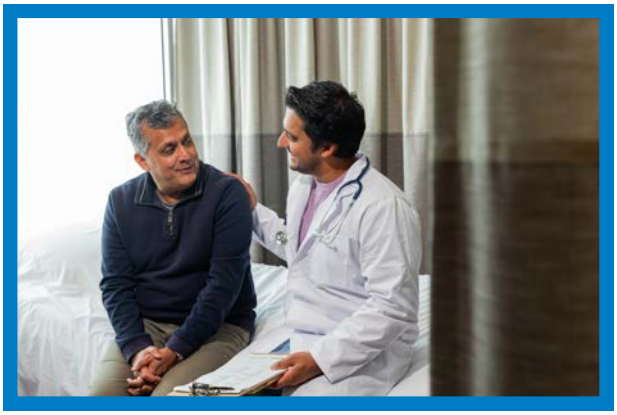
Questions to Ask Your Doctor

Benjamin Rose - 5 Tips for Preparing for a Doctor's Visit

Alzheimer's Association Pre-Appointment Checklist

AARP – 20 dementia diagnosis questions

Dementia Treatment Questions for Your Doctor



Mild Cognitive Impairment

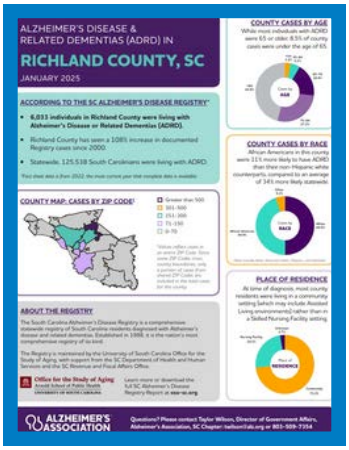
[Alzheimer's Association Special Report: "More Than Normal Aging: Understanding Mild Cognitive Impairment.]

Facts and Figures

[South Carolina Alzheimer's disease Registry (University of South Carolina)]

803-766-1794

[Alzheimer's Association Annual Facts & Figures Report]



[South Carolina County Fact Sheets:]
(a collaboration between the USC Office for the Study of Aging and the Alzheimer's Association)

CAREGIVER SUPPORT

South Carolina Family Caregiver Support Program

Contact your regional Area Agency on Aging for more information.

Dementia Dialogues

A free, five-module dementia caregiver education program through the University of South Carolina's Office for the Study of Aging.
803-777-5334

Alzheimer's Association caregiving

Providing a variety of care planning, communication, safety and self-care topics

Department of Veteran's Affairs – Family Caregiver Support Program

VA caregiver support line: 855-260-3274

VA Office of Survivors Assistance

Centers for Disease Control and Prevention - Maintaining a Care Plan

Family Caregiver Alliance: Self-Care for Family Caregivers

Teepa Snow, Positive Approach to Care

1-877-877-1671

SC Respite Coalition

1-803-935-5027

What You Need to Know About Me Booklet

A tool for family caregivers to document essential information about their loved ones for respite providers. It includes details on daily routines, medical needs, behavioral insights, and personal history to ensure consistent, person-centered care.

UCLA Caregiver Training Videos

The South Carolina Cognitive Connection Ministry - an organization helping faith-based communities provide engagement and support for those in their communities living with dementia, and their family members. Email address: cognitive@umcsc.org

Support Groups

Support groups are offered in-person and virtually around the state both for persons living with dementia and their caregivers. Links to some are provided below. Reach out to your regional Area Agency on Aging for additional support groups in your local area.

Alzheimer's Association Support Group look-up

Alzheimer's Association Early-Stage Dementia Support Groups

Leeza's Care Connection Support Groups

Alzheimer's Foundation of America Support Groups

Dementia Minds support groups for those diagnosed with a form of dementia

Toolkit for Dementia Support Group Facilitators

Driving and Dementia Resources

The Hartford: Driving with Dementia resources

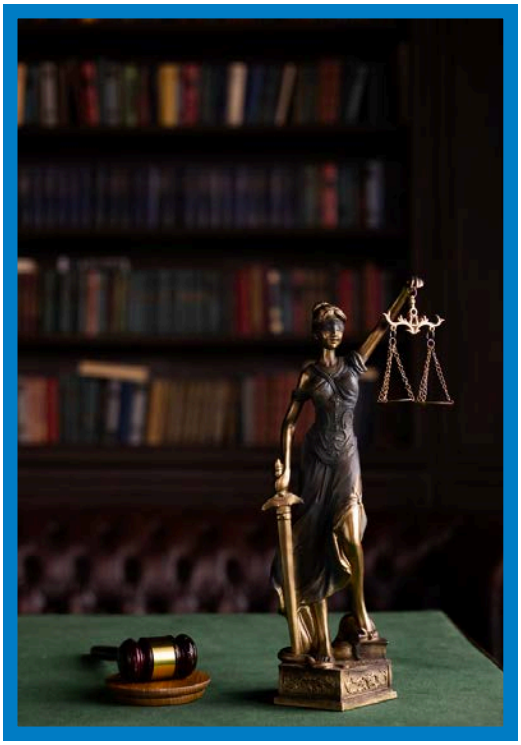
Alzheimer's Association - Dementia and Driving Tips

Prisma Health Driver Rehabilitation Program - Midlands

Prisma Health Driver Rehabilitation Program - Greenville

Roper St. Francis Driving Solutions Program - Charleston

Driver Rehabilitation Program - Myrtle Beach



Legal Resources

SC Bar Association

SC Legal Services
888-346-5592

Dementia Values and Priorities Planning Tool

American Bar Association

Healthcare Power of Attorney for South Carolina

Five Wishes

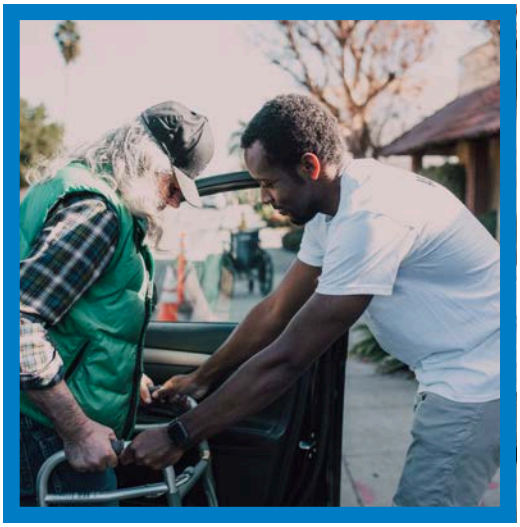
Long-Term Care Options

Types and locator at GetCareSC

Alzheimer's Association Community Resource Finder

AARP Assisted Living Checklist

CMS, Your Guide to Finding a Nursing Home or other Long Term Services and Supports



Research

Alzheimer's Association Research Center

How to connect with an appropriate clinical trial:

Alzheimer's Association Trial Match

clinicaltrials.gov

Alzheimers.gov

Dementia and Genes:

National Institute on Aging Alzheimer's disease genetic fact sheet

Lowering Risk:

Dementia, prevention, and care: 2024 Report of the Lancet Commission

SPRINT-MIND study of hypertension and dementia

The Importance of Dementia and Sleep

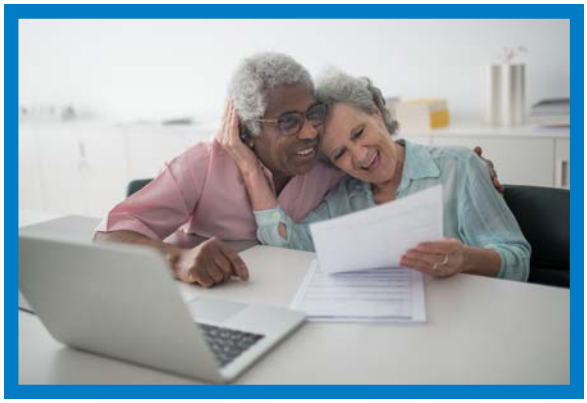
Hearing Loss and Dementia

Treatments

Current Pharmacological Treatments

Medications to treat non-cognitive symptoms related to dementia

Pharmacological and natural interventions



Additional resources

SC Statewide Plan to Address Alzheimer's Disease and Related Dementias

SC DOA Aging - Related Articles

Benjamin Rose Institute on Aging - Dementia Support Articles

Elder Rights and Elder Abuse Resources

To report the abuse, neglect, or exploitation of a vulnerable adult in South Carolina:

- Emergency situations: call 9-1-1
- Non-emergency situations:
    - o call 1-888-CARE4US (1-888-227-3487) or
    - o go to https://benefitsportal.dss.sc.gov/#/ran/home

Elder Rights and Protections

Signs of Elder Abuse

M Y N O T E S

South Carolina

DEPARTMENT ON AGING

AGING.SC.GOV