

# A Guide for People Living with Dementia and Their Caregivers



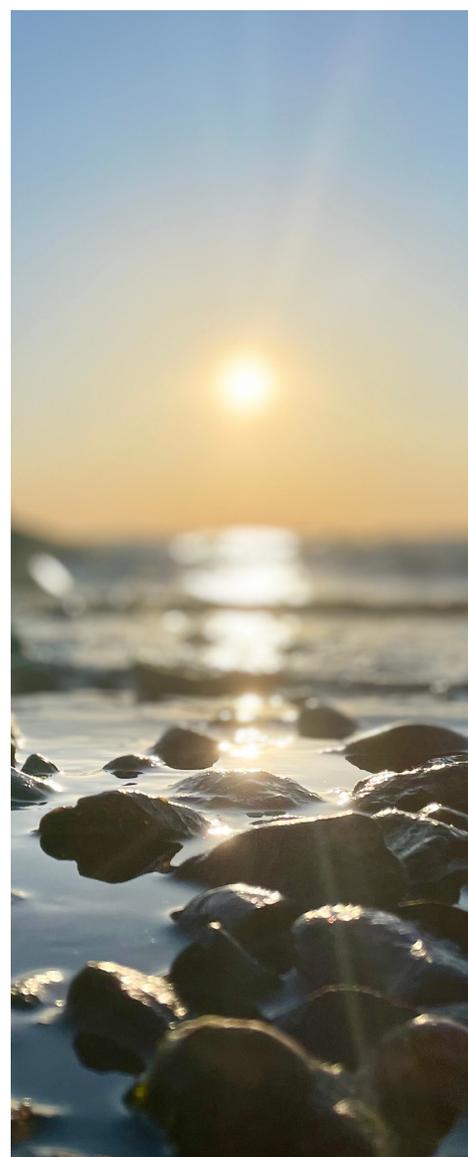
Promoting Brain Health, Understanding  
Dementia, and Supporting Caregivers





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Dear Reader,

The Rhode Island Department of Health recognizes dementia as a public health crisis. The condition affects so many people – not only the person living with dementia but also their caregivers, families, friends, and communities.

According to the Alzheimer's Association, more than 24,000 Rhode Island adults aged 65 or older live with some form of dementia. Given the state's aging population, this number is expected to increase in the coming years. Alzheimer's disease and other forms of dementia have an enormous impact on informal, unpaid caregivers. In Rhode Island, more than 36,000 unpaid caregivers provide more than 51 million hours of unpaid care. More than half of these caregivers live with their own chronic health conditions.

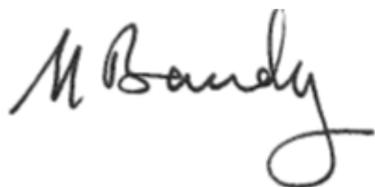
Living with dementia and caring for a person living with dementia can be challenging and frustrating at times. It can also be rewarding, empowering, and fulfilling. While many families will feel the confusion and uncertainty that comes with increased memory loss, others will feel the joy of laughter, growth, and resiliency that are part of living with this condition.

This guide is a resource for:

- Those who are curious about their aging brain. You'll find information about brain health and how to keep your brain healthy as you age.
- Those who are living with a diagnosis of some form of dementia. You'll find information about the stages of dementia and how the disease progresses.
- Those who are caregivers of a loved one with some form of dementia. You'll find information on actions you can take to care for your loved one, along with supports and services available right here in Rhode Island.

The Rhode Island Department of Health and its partners are committed to supporting people living with dementia and their caregivers in this state. This guide includes information, tools, and resources to help you make an action plan that's right for you.

Sincerely,

A handwritten signature in black ink that reads "Utpala Bandy". The signature is written in a cursive, flowing style.

Utpala Bandy, MD, MPH  
Interim Director of Health

# Terms You'll See In This Guide

## **Advance Care Directives (or Planning):**

Legal documents, including Living Wills, that take effect if you're unable to speak for yourself. You can use them to organize and communicate your decisions about things such as end-of-life care.

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## **Alzheimer's Disease:**

The most common type of dementia, Alzheimer's is a progressive disease that is not a part of normal aging. Alzheimer's disease involves parts of the brain that control thought, memory, and language. The condition can seriously affect a person's ability to carry out daily activities. It begins with mild memory loss and can lead to an inability to have conversations or respond to the environment.

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## **Caregiver:**

A person caring (physically and/or emotionally) for another person or loved one. They're also known as caretakers or care partners.

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## **Cognition:**

The mental functions involved in attention, thinking, understanding, learning, remembering, solving problems, and making decisions.

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## **Cognitive Impairment:**

A condition that causes a person to have trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. With mild impairment, people may notice changes in cognitive function but are able to do their everyday activities. Severe levels of impairment can lead to loss of independence.

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## **Dementia:**

A general term for a decline in mental ability severe enough to interfere with activities of daily living. Memory loss is an example. Alzheimer's is the most common type of dementia, but not all dementia is associated with Alzheimer's disease. Other types of dementia include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.

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## **Durable Power of Attorney for Healthcare:**

A legal document that allows you to appoint someone you trust to serve as your healthcare representative and assist with health and financial decision-making if you are unable to make decisions.

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## **Frontotemporal Dementia (FTD):**

A form of dementia that involves nerve cell loss in the brain's frontal or temporal lobes. Nerve cell loss in the frontal lobes located behind your forehead leads to behavioral symptoms. Nerve cell loss in the temporal lobes located behind your ears leads to language and emotional disorders.



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**Healthcare Provider:**

An individual health professional, health facility, or health organization licensed to provide health diagnosis and treatment services such as medication, surgery, and the use of medical devices.

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**Lewy Body Dementia (LBD):**

A form of progressive dementia that causes physical, cognitive, and behavioral symptoms. LBD is the second most common form of progressive dementia, and its symptoms mimic those of Alzheimer's disease, Parkinson's disease, or other psychiatric disorders.

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**Medicare:**

A federal health insurance program for adults with disabilities and adults 65 and older.

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**Medicaid:**

A state and federal health coverage program for individuals with low incomes.

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**Medical Orders for Life-Sustaining Treatment (MOLST):**

A Rhode Island state policy that translates an individual's advance directive into a set of medical orders. MOLST helps ensure that a person's preferences are honored, no matter where they receive care.

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**Mild Cognitive Impairment:**

A slight but measurable decline in cognitive abilities such as memory and thinking. A person with mild cognitive impairment is at an increased risk of developing Alzheimer's or another dementia.

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**Subjective Cognitive Decline (SCD):**

A self-reported experience of worsening or more frequent confusion or memory loss within the past year. SCD is a form of cognitive impairment and is one of the earliest noticeable symptoms of more severe memory disorders such as Alzheimer's disease and related dementias.

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**Vascular Dementia:**

A form of dementia that involves a decline in thinking skills caused by conditions that block or reduce blood flow to various regions of the brain. A stroke most often causes vascular dementia.

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**Young-Onset Alzheimer's:**

A form of Alzheimer's disease that affects people younger than 65.

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# Understanding Changes in Memory and Thinking

The experience of living with cognitive impairment, or caring for someone with memory loss or dementia, is different for each person. There are many ways for you and your family to get help, care, and support in Rhode Island that will improve your quality of life. We hope this guide gives you helpful information and useful resources to help you and your family navigate the future with confidence.

## About Dementia and Its Connection to Brain Health

Dementia is a term for a set of symptoms that affect your memory and thinking. These symptoms can make it difficult to complete your typical daily activities. Alzheimer's is the most common form of dementia and the fifth leading cause of death for people 65 and older. Alzheimer's is caused by an abnormal build-up of protein in the brain, likely due to a combination of genetic, environmental, and lifestyle factors.<sup>1</sup>

Today, there is no known cure for Alzheimer's. Planning for your care can help you maintain brain health, manage behavioral symptoms, and even slow or delay disease progression.

Since dementia affects each person differently and progresses at different rates, your healthcare provider will work closely with you to manage symptoms. There are many local programs and resources to help you build a support system and cope with changes.

### Tips for a Healthy Brain:

- Sleep for at least 7 to 9 hours each night
- Minimize stress
- Eat a healthy diet with fresh ingredients and food rich in antioxidants
- Stay as physically active as you can
- Challenge your brain with new experiences and new ideas
- Socialize with friends, spend time with family, and meet new people

<sup>1</sup> <https://www.cdc.gov/aging/publications/aag/alzheimers.html>

# Lowering Your Risk



Studies have shown that a build-up of plaque in the brain can begin as long as 10 to 20 years before any symptoms appear. Maintaining a healthy brain throughout your life is the most effective way to prevent or slow disease. The best news? It's never too late to take action. Research has revealed that in many cases, a few simple changes to your daily life can slow the progression of Alzheimer's and other dementias. These changes can also help prevent other chronic conditions like diabetes, heart disease, and stroke.

Healthy eating and active living are important to a healthy brain. Rhode Island offers many programs to help you stay healthy and lower your risk of dementia, including [Walk with Ease](#), [Tools for Healthy Living](#), and [Ready for Health](#). Your healthcare provider can tell you about the lifestyle changes that would be most beneficial for you.

The **Community Health Network (CHN) - Health & Wellness Workshops in RI ([ripin.org](http://ripin.org))** provide tools to take control of your health and manage your health conditions with guidance and support on physical activity, nutrition, and emotional well-being. The CHN also accepts self-referrals.

## Is It Normal? Signs and Symptoms of Mild Cognitive Impairment, Alzheimer's, and Dementia

Just as our bodies slow down with age, so do our brains. When a decline in cognitive function interferes with your normal activities, it may be a sign of dementia. Depending on the cause of dementia, there are different treatment options available. These options include several promising new interventions and programs for people with different forms of dementia.



# How Can I Tell If Changes Are Normal?

## Signs of Normal Aging:

Occasionally forgetting a date, word, appointment, or task.

Slight difficulty paying attention or multitasking, or occasionally needing help to use microwave settings or to record a TV show.

Getting confused about the day of the week but figuring it out later.

Sometimes having trouble finding the right word.

Making occasional errors when managing finances or household bills.

Forgetting to eat lunch on a busy day and making a snack later.

Sometimes feeling uninterested in social obligations.

Making a bad decision occasionally.

Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

Tripping occasionally when walking or feeling muscle fatigue after strenuous activity.

Misplacing things from time to time and retracing your steps to find them.

Vision changes related to cataracts.



# Signs to Discuss with a Healthcare Provider

Forgetting recently learned information, important dates, or events; asking the same question many times; or an increasing need to rely on memory aids like reminder notes or electronic devices.

Difficulty completing routine tasks. Trouble driving to a familiar location, organizing a grocery list, or remembering the rules of a favorite game.

Losing track of dates, seasons, and the passage of time.  
Forgetting where you are or how you got there.

Increasing difficulty coming up with words, naming a familiar object, or using the wrong name.

Increasing difficulty with developing or following a plan. Difficulty working with numbers.  
Trouble following a familiar recipe or keeping track of monthly bills.

Difficulty with basic activities like personal hygiene, eating, or getting dressed.

Trouble following or joining a conversation; withdrawing from hobbies, social activities, or other engagements.

Experiencing changes in judgment or decision-making or exhibiting odd or inappropriate behaviors.

Experiencing marked mood and personality changes, getting upset easily at home, at work, with friends, or when out of your comfort zone.

Experiencing physical symptoms like stiff or weak muscles, balance problems, frequent falls, feet that shuffle or drag when walking, or tremors and uncontrollable twitches.

Storing items in unusual places, wandering, getting lost, or losing things and being unable to retrace your steps to find them again.

Having difficulty understanding visual images and spatial relationships, judging distance, and determining color or contrast.



# The Stages of Memory Loss



Early detection and diagnosis may slow the progression of symptoms related to Alzheimer's or other dementias. Today, researchers are developing new techniques and screening measures to identify and diagnose these diseases as early as possible. For patients and their families, an early diagnosis can bring relief in understanding cognitive changes and empower them to develop a plan of care. Talk to your healthcare provider about monitoring your brain health as part of your routine medical care. If your own or your loved one's memory loss concerns you, your provider may conduct a series of tests. In addition to a physical exam, your provider may give you:

- A neurological exam
- A cognitive test like the Mini-Mental State Examination (MMSE)
- Brain imaging
- Other diagnostic tests

Your healthcare provider may also recommend a comprehensive mental health screening, especially if you experience anxiety, sleep issues, and depression. Adults 65 and older may also find it helpful to consult with a specialist who treats people with complex medical histories or conditions that accompany aging. This type of specialist is known as a geriatrician. Although the characteristics of disease are different in each person, Alzheimer's and other dementias can be separated into three categories based on how severe the symptoms are. These categories include:

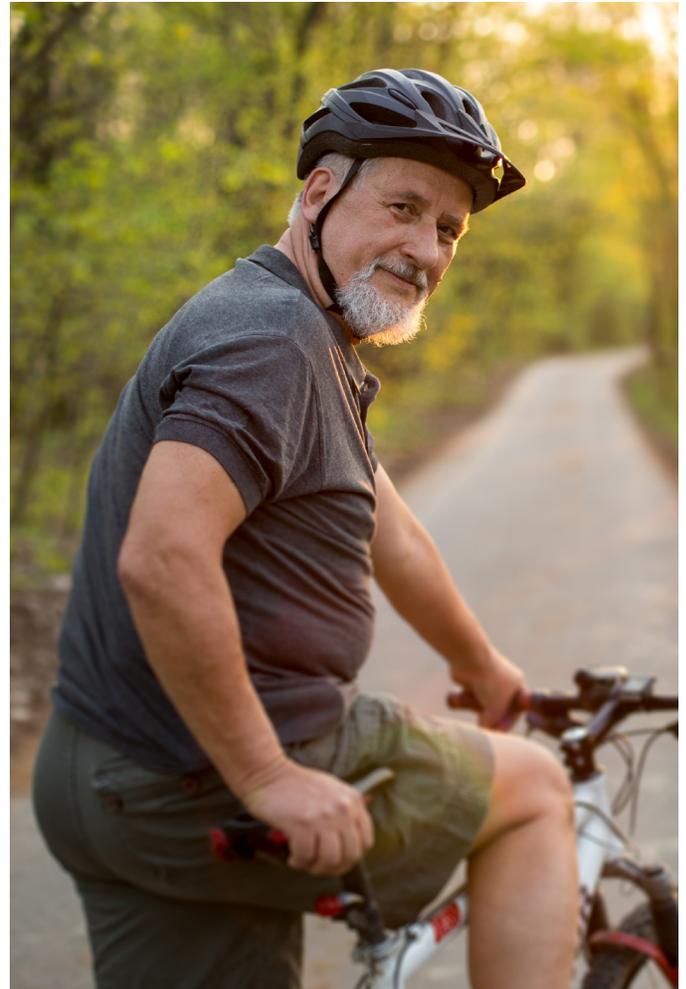
- Mild or early-stage cognitive impairment
- Moderate or middle-stage cognitive impairment
- Late or advanced-stage cognitive impairment

Mild cognitive impairment and young-onset dementia are important to understand. Symptoms and stages may overlap and progress over time.



## Mild Cognitive Impairment

Mild Cognitive Impairment (MCI) is an early stage of memory loss. People diagnosed with MCI may experience mild symptoms such as some language loss or reduced perception. Most people with MCI can still perform daily activities. An estimated 10% to 15% of people living with MCI develop dementia. If you are diagnosed with MCI, talk to your healthcare provider about whether anti-amyloid treatments or other prescription medications are right for you. A combination of medications and lifestyle changes, such as diet and exercise, can support your brain health and help slow progression of the disease.



## Young-Onset Dementia

Although Alzheimer's and other dementias typically affect older people, dementia can affect adults of all ages. Young-onset (sometimes referred to as early-onset) dementia mostly affects people in their 40s and 50s. If you're concerned about memory loss, it's important to talk to a healthcare provider about your symptoms — even if you think you're too young to have memory loss symptoms.

## Mild or Early-Stage Dementia

If you or a loved one has been diagnosed with mild dementia due to Alzheimer's disease, you may experience a slight but noticeable decline in memory and thinking. Common challenges include:

- Forgetting words or misplacing objects
- Having trouble making plans or organizing yourself
- Challenges performing tasks in social or work settings
- Trouble remembering names when meeting new people

These early symptoms may not affect your daily activities. If you're concerned, speak to your healthcare provider.



## If You Have Dementia:

You may be experiencing uncertainty and frustration with changes in your cognitive ability. Short-term memory may be affected, and you may repeat phrases or questions. You may be relying on tools to remember details. Setting alarms and leaving notes around the house may be a helpful strategy. You may also wonder how to manage your symptoms or control disease progression.

## If You're a Caregiver:

You may see signs of dementia that nobody else notices. You may feel concerned and increasingly responsible for remembering details your loved one can't. While there are many tasks your loved one can still complete on their own, they may require more help with daily activities. You may wonder how you can best support their independence in daily activities.

## What You Can Do:

- Speak to a healthcare provider about anti-amyloid treatment options that may help with symptoms of early-stage dementia.
- Meet with close family and friends to discuss what's happening and any needed next steps.
- Find a support group to discuss life changes, emotions, and strategies for coping with dementia.
- Complete a Healthcare Directive (also called a "Living Will" or "Advance Directive") to define your treatment preferences.
- Complete a Durable Power of Attorney for Healthcare and appoint someone you trust to serve as your healthcare representative and assist with financial and related matters.
- Seek legal advice or use free resources online or in the community to develop a will. This important legal document specifies how you'd like your property and belongings handled.
- Stay active, eat well, and socialize as much as possible.
- Connect with the Rhode Island Chapter of the Alzheimer's Association and other experts for tools and free resources to manage medications, household chores, and daily responsibilities.

## Moderate or Middle-Stage Dementia:

At this stage, symptoms are more noticeable and require a greater level of care. Common challenges include:

- Increased memory loss and confusion
- Problems recognizing family and friends
- Decreased ability to perform complex tasks or handle personal finances
- Personality and behavior changes, including delusions, suspiciousness, and compulsive behavior
- Changes in sleeping patterns
- Needing help with choosing proper clothing to wear for the day, season, or occasion

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## Checking In

### If You Have Dementia:

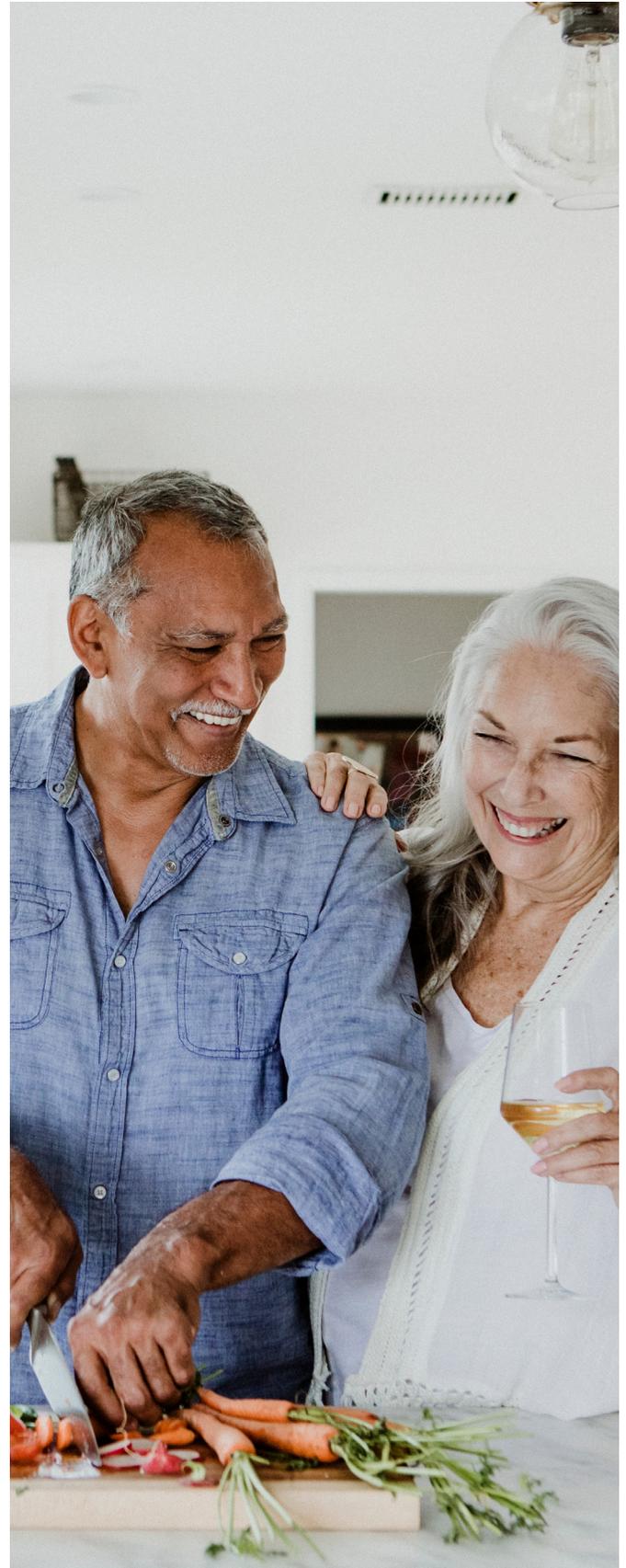
You may be experiencing more confusion and memory loss. Your needs are growing, and your judgment may be inconsistent. You may need more help (or supervision) with routine tasks, hygiene, and following instructions. Sleep and balance troubles may develop. You may act in unusual ways or experience delusions. Some days may feel normal, while other days may feel challenging.

### If You're a Caregiver:

You may notice increasing changes in your loved one and need to learn new ways of coping with their needs. Remember that your needs matter too. You won't be able to care for your loved one if you don't take care of yourself. Focus on finding moments of quality time with your loved one and on activities that make you feel good. Try new ways of communicating with your loved one. Remember the changes you're seeing in your loved one are the result of their condition.

## What You Can Do:

- ❑ Complete a Medical Order for Life-Sustaining Treatment (MOLST) form.
- ❑ Secure a referral to a physical or occupational therapist for a home safety evaluation. They can recommend strategies to help prevent injuries, accidents, or falls.
- ❑ Ask for specific support from family and friends and accept any help offered.
- ❑ Seek respite care. A healthcare aide can provide care in your home or at a licensed senior care center so the primary caregiver can take a break.
- ❑ Join a MedicAlert+Safe Return program. These programs help bring peace of mind if your loved one wanders.
- ❑ Look into residential care programs, either at home or in an assisted living facility. Moving your loved one to a memory care unit is a difficult decision. It's good to understand available safe housing options before you need to make that decision.
- ❑ Make sure you and your loved one get ongoing medical care.



## Advanced or Late-Stage Dementia

At this stage, memory and cognitive skills may decline significantly.

Common challenges include:

- Recognizing faces, but forgetting names
- Increased difficulty with communicating and performing daily activities
- Loss of awareness of surroundings and forgetting recent experiences
- Challenges with daily activities like eating, toileting, and walking

## Checking In

### If You Have Dementia:

If dementia has progressed, you may be dependent on others for your personal care. You may recognize people but have trouble remembering their name or how you know them. Communication may be difficult or no longer possible. It may be challenging to walk, move, sit for periods of time, or swallow. Your risk of pneumonia and other infections increases. You can still feel deep emotions and enjoy the company of others.

### If You're a Caregiver:

You may feel profound grief about losing the loved one you once knew. You may wonder how to ensure a positive quality of life for your loved one. You may face end-of-life preparations and need to reach out to family members and friends of your loved one.



## What You Can Do:

- Accept support from family and friends, healthcare providers, adult day care and respite care providers, volunteers, and spiritual advisors.
- Review your loved one's end-of-life arrangements and wishes.
- Make the most of time with your loved one – listen to favorite songs, read passages from favorite books, and tell stories about your lives.
- Enrich your time together with sensory comforts like fresh air, music, flavors, or scents.
- Consider support groups or grief counseling to help you cope with your emotions.
- Take charge of your own health by eating healthy foods, staying physically active, getting enough sleep, and engaging in social activities.
- Seek palliative services and/or hospice care. Seek guidance on adjusting or stopping medications as appropriate.



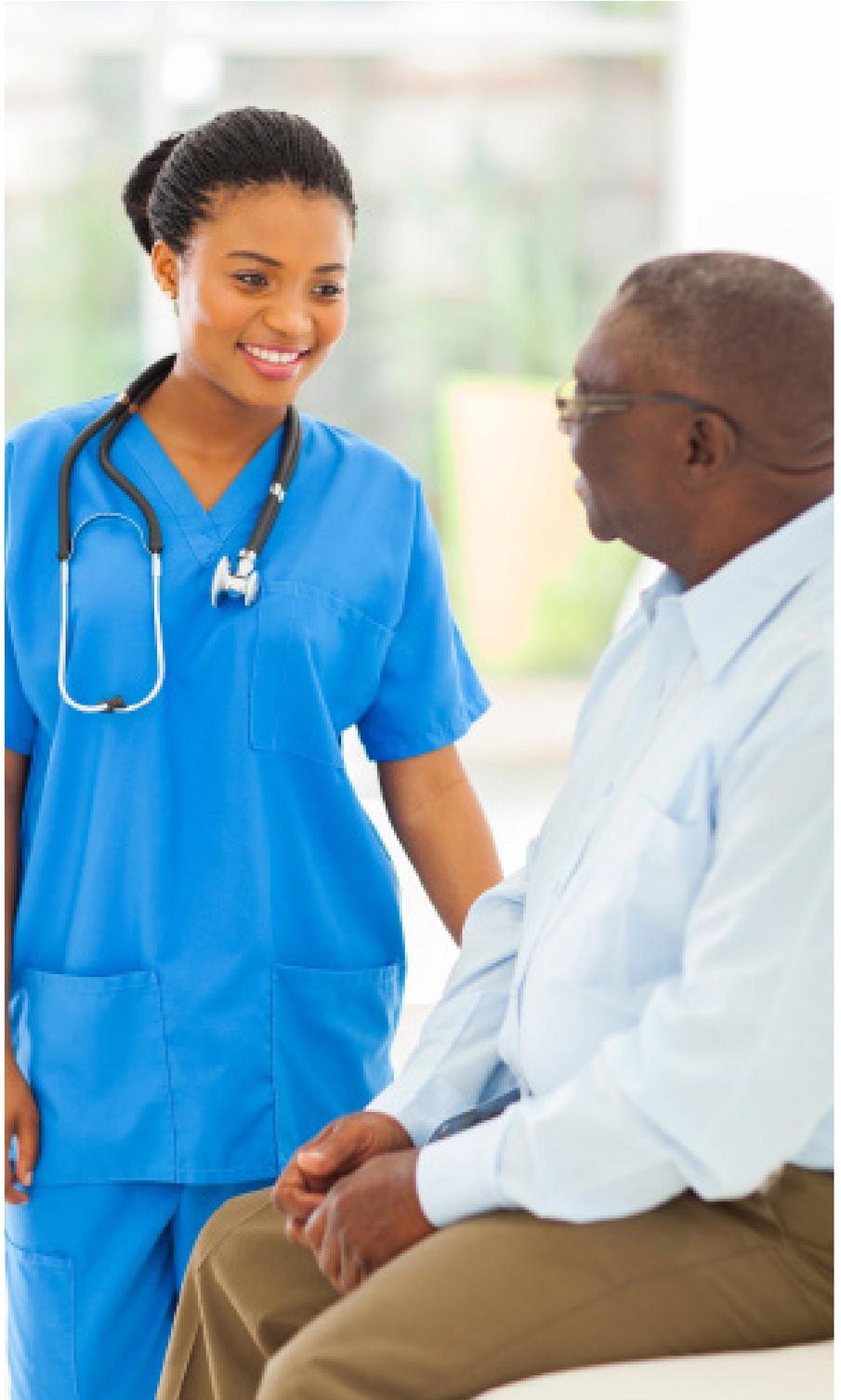
# Questions to Ask Your Healthcare Provider:

## Learning about Brain Health:

- What can I do to lower my risk of developing dementia?
- What signs and symptoms should I be concerned about?
- How is dementia diagnosed?

## Living with Dementia:

- What changes can I expect with a diagnosis of dementia?
- What can I do to manage the progression of the disease?
- What are my treatment options?
- Are there medications I should consider?
- How often should I be evaluated?
- How can I participate in research or clinical trials?
- What do I need to do to plan for my future?



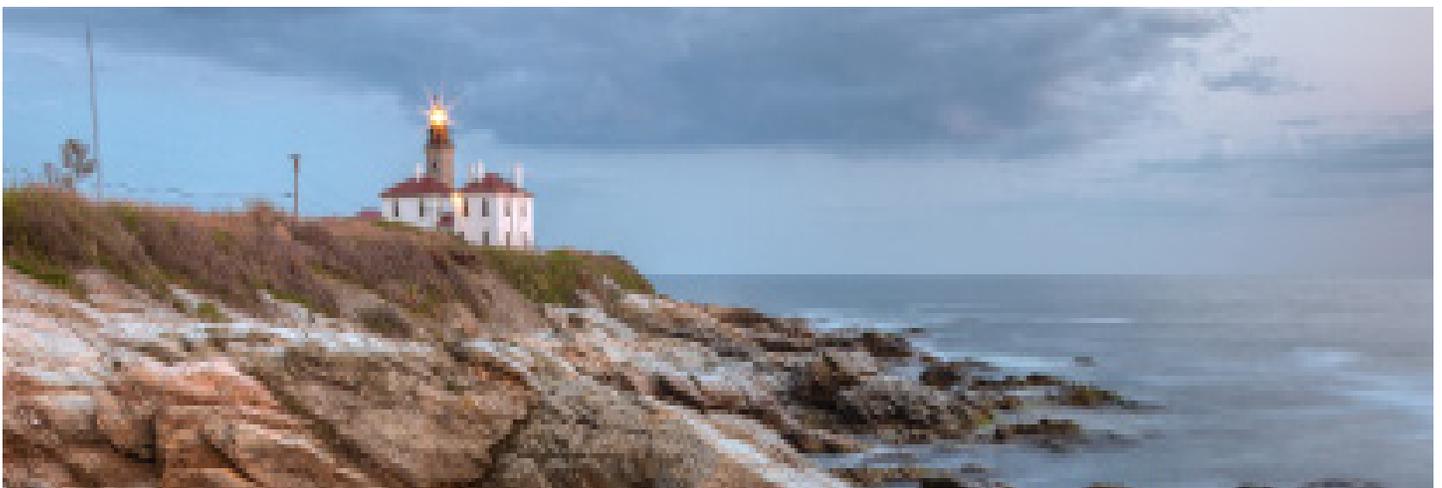


# Living with Dementia One Day at a Time

A dementia diagnosis can raise many questions. Every day will be different, and some may be challenging. How you respond to changes in yourself or your loved one and your willingness to take advantage of available resources can make a difference.

Staying current with reliable information can help you take control of your health and manage your health. Your healthcare provider can offer guidance and support on physical activity, nutrition, and emotional well-being.

The Alzheimer's Association – RI Chapter is your resource for identifying local supports and services. The 24/7 Helpline is available at any time of day, 365 days a year. Through this free service, specialists and clinicians offer confidential support and information to people living with dementia, their caregivers and families, and the public. All calls are answered by trained specialists. You'll never be forwarded to an answering service, and support is available in over 200 languages.



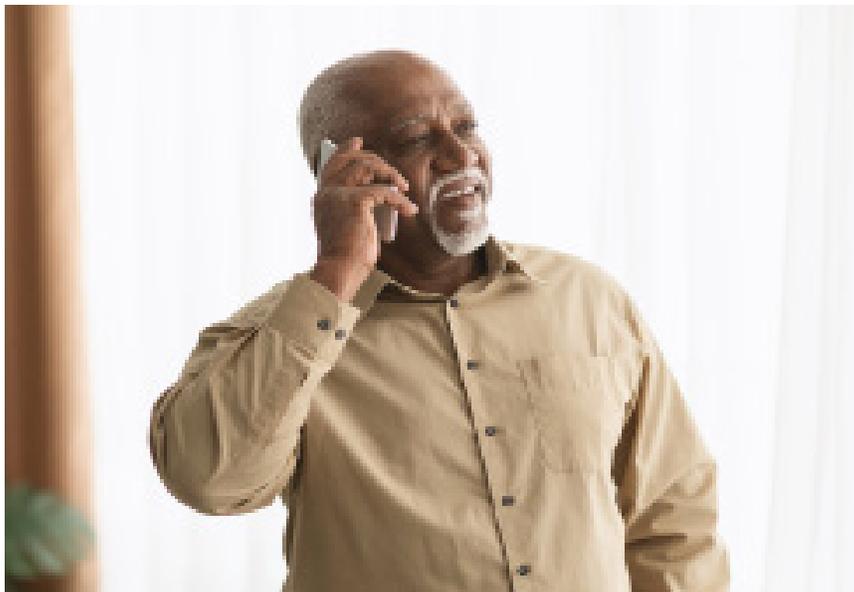


The Alzheimer's Association and AARP offer an updated database of dementia and aging-related resources called the Community Resource Finder [communityresourcefinder.org]. This tool makes it easy for people living with dementia and their caregivers to find local programs and services, such as care at home, adult day programs, community services, housing options, and more. The Office of Healthy Aging (OHA), formerly known as Elderly Affairs, is Rhode Island's State Unit on Aging. OHA's work centers around empowering all Rhode Islanders to age strong, connecting them to information and resources in the community to support their goals for how they want to live as they age.

Partnering with organizations throughout Rhode Island, OHA has developed the Pocket Guide: Rhode Island's Guide to Services for Older Adults and Adults with Disabilities, which can be found at this link:

OHA Resource Center | Office of Healthy Aging ([oha.ri.gov/resources](https://oha.ri.gov/resources))

The Point, Rhode Island's Aging and Disability Resource Center, is a statewide resource that provides information and assistance to seniors, adults with disabilities, and their caregivers based on individual needs and preferences. The Point serves as a trusted place, connecting you and your loved ones to services and support in your community.



**You can call The Point to learn about your long-term care options and get connected to resources in your area.**

**Call 401-462-4444.**

# The Alzheimer's Association Helpline number is 1-800-272-3900.

Call the Helpline when you need help with any part of living with or caring for someone with dementia, such as:



I am noticing changes in my ability to complete daily tasks. What should my first step be?

My father has Alzheimer's and we believe he should stop driving. How do we talk to him about this?

My mother has just been diagnosed with dementia and I don't know where to start or what to do.

I need to find a support group in my area.

My wife has Alzheimer's and has started wandering. I'm not sure what to do.

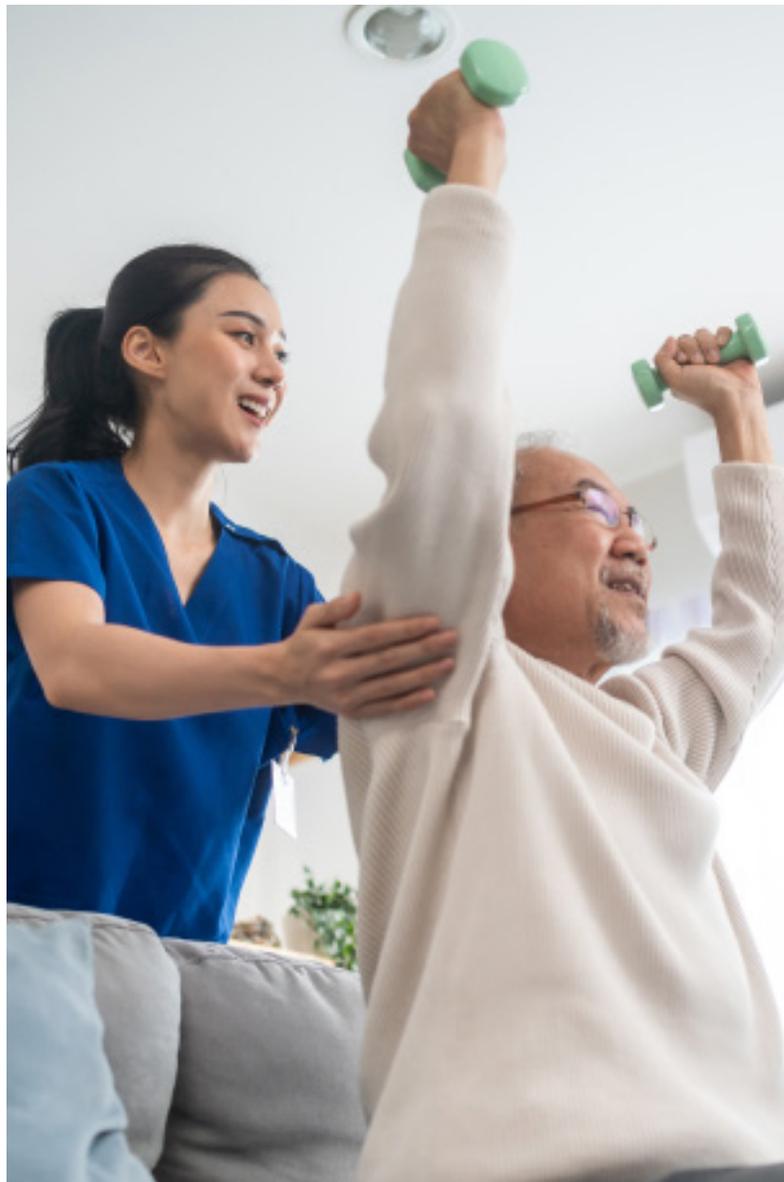
I think it's time to move my partner to a long-term care facility, but I don't know how to find one that meets our needs.

# Emerging Treatments and Interventions



While there is still much to learn about Alzheimer's, there have been groundbreaking developments in recent years in the search for a treatment or cure. These include:

**Medications:** Currently, the Food and Drug Administration has approved medications to temporarily slow the worsening of dementia symptoms. Your healthcare provider may also



prescribe other medicines to help manage behavioral symptoms associated with dementia, such as sleep or mood changes. When you take a new medication, your healthcare provider will monitor you closely for side effects or adverse reactions with other medications you take.

**Research and Clinical Trials:** Clinical trials rely on people who volunteer for research studies designed to ensure that medications work for their intended purpose, or to explore the accuracy of a new screening or detection process. You may be able to help Alzheimer's research by joining a study or clinical trial. Reasons why someone might consider a research study or clinical trial include:

- Regular monitoring by medical professionals
- Access to safe, experimental treatments or drugs
- Comprehensive support, information, and resources
- Assistance to family members who may be at risk for Alzheimer's

# Emerging Treatments and Interventions (continued)

Talk to your healthcare provider to see if you may be eligible to participate in a clinical trial and whether a study is right for you. You can learn more about research studies and clinical trials in Rhode Island by contacting:

**Care New England's Memory and Aging Program (MAP) at Butler Hospital.** This research program has contributed significantly to the understanding and treatment of Alzheimer's.

**Lifespan's Alzheimer's Disease and Memory Disorders Center at Rhode Island Hospital.** This research program offers clinical trials that study new therapies aimed to treat, delay, and ultimately prevent symptoms of Alzheimer's disease.

**Rhode Island Mood & Memory Research Institute (RIMMRI).** This program brings together patients, researchers, and sponsors to facilitate the development and study of emerging medical treatments. RIMMRI specializes in central nervous system (CNS) clinical trials, including Alzheimer's disease.

The Alzheimer's Association hosts Trial Match®, a database that connects individuals living with Alzheimer's, their caregivers, and healthy volunteers with clinical trials that may advance Alzheimer's research. The free service allows you to search for studies that may be a good fit for you or a family member, receive email notifications about new opportunities, or connect with research teams. Talk with your healthcare provider to see if a clinical trial is right for you.

# Staying Strong: Caring for Caregivers

When you're caring for someone with dementia, it may be challenging to find time to care for yourself. It's important to prioritize your own physical and emotional well-being. Building a strong support network through friends, neighbors, your faith community, and volunteer agencies is important.

Although your caregiving role may grow as your loved one's dementia progresses, remember to engage in activities just for you whenever you can. Finding time to pursue your interests is critical to your own health and well-being. See your healthcare provider so you stay on track with annual appointments, screenings, and other health needs. Caregiver support groups offer a safe, supportive space to reflect on your own mental and emotional health.

You may find it helpful when other family members and friends visit your loved one on a regular schedule, giving you time to yourself. Seek helpers you can trust and give them specifics on how they can pitch in. Ask for help with laundry and/or cooking. If managing finances is challenging, see if a trusted family member can help. Visits from neighbors and friends can also lift your spirits and provide some respite.

**I found an aide with experience in dementia to take my husband on a road trip once a week. They always ended their journey with ice cream (my husband's favorite food on earth). It was a regular outing he enjoyed while giving me a much-needed break.**

-Helen N., Caregiver



# Here to Help

Services and supports in your community can help make caring for your loved one easier to manage. Determining an appropriate course of action can make a significant difference for you and your loved one. From working with a patient navigator to identify and schedule specialist appointments to finding a low-cost healthcare provider and securing home healthcare, it's important to know which resources are available to you. The resources here are a snapshot of the services available in Rhode Island. Assistance may include:



## Legal and Financial Services

Rhode Islanders have the right to control decisions related to their medical care and to authorize others to make medical decisions for them if they become unable to do so. These decisions, when put into writing, are known as **Advance Directives**. If you're considering end-of-life issues, you may want to consult with your healthcare provider to understand treatment options, including their side effects, benefits, and limitations.

You may also want to consult with a lawyer to understand legal issues, draft a will, or establish a trust. For families living with Alzheimer's disease and other dementias, it's important to make healthcare decisions as early as possible before the disease progresses. Complete a **Durable Power of Attorney** form and a **Living Will** to detail your preferences regarding your healthcare and treatment options, and to identify a trusted advocate to help with legal and financial decisions.

## Support Groups

Whether you're living with dementia, or you're a caregiver or a family member, there are many free support groups near you and for you. Support groups offer practical suggestions and coping skills for living with dementia in a community of people facing similar experiences. Many people find that sharing and learning with others offers a sense of control and comfort.

You can find specialized support groups for people with young-onset dementia, family caregivers, LGBTQ+ members, virtual support networks, online chat groups, and groups led by peers or professionals. How much you choose to participate is completely up to you, and there is no pressure to share your story unless you want to. If you don't find a support group that meets your needs, you may be able to start one. Speak to the Alzheimer's Association – RI Chapter to learn more.



## Adult Day Centers

Adult day centers provide health, social, and support services in a safe and protective environment. These programs offer an opportunity to socialize and take part in a variety of enrichment activities while adapting to the abilities and needs of the person living with dementia. The Alzheimer's Association Community Resource Finder can help you find an adult day center near you.

## Respite Care

Respite care offers caregivers a break from their responsibilities. Having time to run errands, visit with friends or family, or have time away from home can be a positive and important way to recharge while your loved one stays safe. Respite programs in Rhode Island offer services free of charge, provided by volunteers in the community and can be accessed through the Office of Healthy Aging.



## Long-Term Care

Long-term care may be provided in a person's home, an assisted living community, or a nursing home. If dementia has progressed to a later stage, you may need to consider a special care unit (SCU), also called a memory care unit, designed to meet the specific needs of individuals with Alzheimer's and other dementias. There are many resources available to help you identify a long-term care option that works for you.

## Home Healthcare Services

Home healthcare aides are licensed medical professionals who come to your home to provide skilled nursing care, medication management, physical therapy, occupational therapy, speech therapy, and other medical services. In addition, there are many programs that provide supervised activities or outings, and assistance with home modifications and other safety measures. These services are usually coordinated with your doctor's office, which may provide referrals for coverage under Medicare or other insurance.

# Here to Help (continued)

## Home Care Services

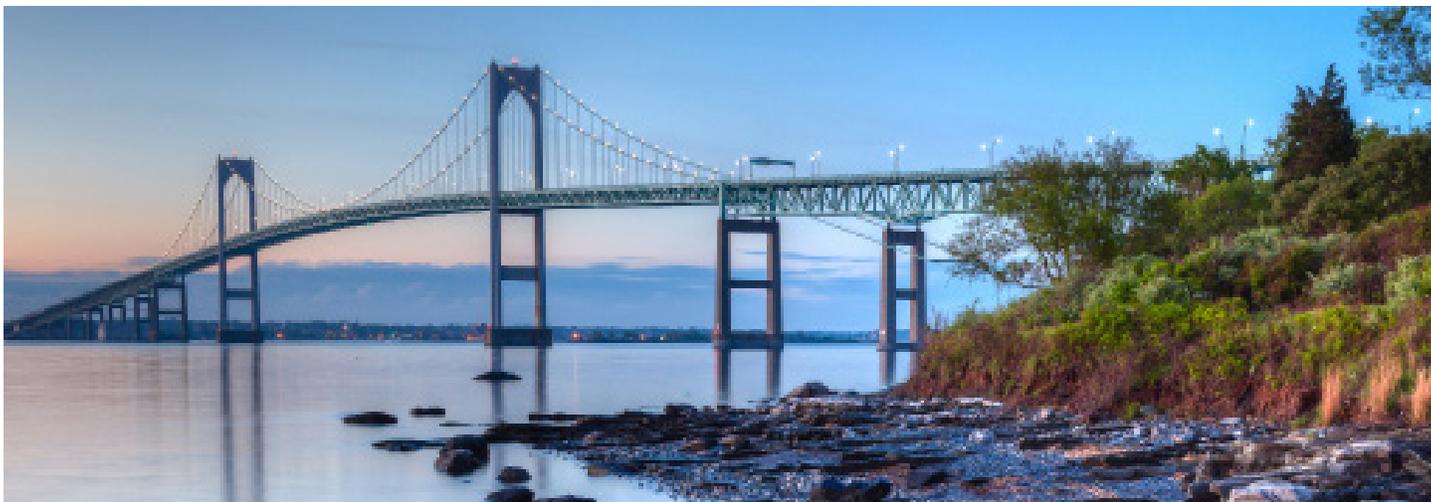
Home care aides provide personal care, assistance with daily activities, and perform light housekeeping, transportation, and errands. It's important to know these services don't include skilled medical care. Consult with your insurance provider to determine which services are covered by your policy.

## Palliative and Hospice Care

Palliative and hospice providers with expertise in dementia help keep your loved one comfortable. Services may include medical equipment to protect them from accidents or falls and improve their comfort. These providers also offer emotional and spiritual counseling about what to expect in the final stages of dementia, grief counseling, and caregiver support. Some provide respite care for caregivers. Palliative care providers help manage symptoms and provide specialized medical care while you remain under your doctor's care. You can receive palliative services at any age and any stage of dementia.

Hospice programs provide many of the same services as palliative care. These providers help patients and families during the shift from earlier stages of the illness, in which care is coordinated and managed by your healthcare providers, to the advanced stage of dementia, where you and your family are more empowered with medical decision-making and comfort measures. Both palliative and hospice care focus on maintaining quality of life for you and your loved one and can be provided at home or in a nursing facility. Fees for these programs may be offered on a sliding scale, partially or fully covered by a health plan, or free.

Talk with your healthcare provider or support network about programs and services available to you. Your health plan may help identify services you're eligible for.



# Resources That Can Help



**In any emergency, please dial 911.**

## **Alzheimer's Association 24/7 Helpline**

Phone: 1-800-272-3900

The Alzheimer's Association offers information, a helpline, and support services to people with Alzheimer's and their caregivers in multiple languages. Local chapters across the country offer support groups, including many that help with early-stage Alzheimer's disease. The Association also funds Alzheimer's research.

## **Community Resource Finder**

The Alzheimer's Association maintains an online database of dementia and aging-related resources, programs, and services for people living with Alzheimer's and other dementias, family caregivers, and those involved in making care-related decisions.

## **Office of Healthy Aging**

Phone: 401-462-3000

TTY: 401-462-0740

The Office of Healthy Aging is the state unit on aging and can connect older adults with services through the OHA Resource Center | Office of Healthy Aging ([ri.gov](http://ri.gov)).

## **The Point**

Phone: 401-462-4444

The Point can help you access valuable information and provide assistance for you and your loved ones about home and community-based care, access to public assistance programs such as Medicare, Medicaid, SNAP, heating and utility assistance, resources for caregivers and their families, assistance with planning for memory and cognitive care, and information regarding other valuable resources in the community.

## **The Community Health Network**

The Community Health Network connects Rhode Islanders with evidence-based chronic disease prevention and management programs that meet their needs, such as Walk with Ease, Tools for Healthy Living, and Ready for Health, as well as Powerful Tools for Caregivers workshops. The Community Health Network operates through a partnership with the Rhode Island Department of Health and RIPIN (formerly known as the Rhode Island Parent Information Network). To learn more, visit [ripin.org/chn](http://ripin.org/chn)

## **PACE Organization of Rhode Island**

Phone: 401-434-1400 (available 24/7)

Toll-Free: 877-781-PACE (7223)

TTY: 800-745-5555

PACE Organization of Rhode Island is a not-for-profit health plan that offers services for qualifying adults aged 55 and older who have complex health needs and want to remain at home.

## **Rhode Island Medicaid Long-Term Services and Supports**

Phone: 1-855-MY-RIDHS (1-855-697-4347)

Hearing Impaired Dial 7-1-1

1-800-745-6575 (Voice)

1-800-745-5555 (TTY)

The RI Department of Human Services offers the Long-Term Services and Supports (LTSS) program, which serves people who have disabilities or chronic care needs in the setting ideal for them and their families.

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## **Veterans Services**

Learn more about the services and programs available to veterans, download the Veterans Administration's **guide** on available programs and services, and contact the following agencies for assistance in Rhode Island:

### **VA Medical Center**

830 Chalkstone Ave.

Providence RI 02908

401-273-7100 x3283

VA's Caregiver Support Line: 1-855-260-3274

### **State of Rhode Island Office of Veterans Affairs**

560 Jefferson Blvd.

Warwick RI 02886

401-921-2119



# National Resources



## **Alzheimers.gov**

Phone: 1-800-438-4380

The Alzheimers.gov portal offers information and resources on Alzheimer's and related dementias and caregiving from across the federal government.

## **Alzheimer's Foundation of America**

Phone: 1-866-232-8484

The Alzheimer's Foundation of America provides information for caregivers, as well as a list of services for people with the disease. It also offers information for caregivers and their families through member organizations, a hotline, publications, and other educational materials.

## **Eldercare Locator**

Phone: 1-800-677-1116

The government-funded Eldercare Locator is a service of the Administration on Aging. It provides information about community resources, such as home care, adult day care, and nursing homes.

## **National Institute on Aging Information Center**

Phone: 1-800-222-2225

TTY: 1-800-222-4225

[niaic@nia.nih.gov](mailto:niaic@nia.nih.gov)

The NIA Information Center offers free publications about aging. Many of these publications are in both English and Spanish.

## **NIA Alzheimer's and Related Dementias Education and Referral (ADEAR) Center**

Phone: 1-800-438-4380

[adear@nia.nih.gov](mailto:adear@nia.nih.gov)

Learn more about the disease, and get news, tips, and resources for caregivers and healthcare professionals, also available in Spanish.

# Your Action Plan

We hope this guide has helped you increase your understanding of brain health, the stages of dementia, and the resources available in Rhode Island to help support you and your loved ones. While living with dementia or caring for a person living with dementia can be challenging at times, a plan of action helps you take control of any care you or a loved one may need. We hope you'll use the sample action plan here to personalize your own next steps. Here's a summary of action steps you can take to prepare for and manage your health:

- Have a meeting with close family and friends to discuss what's happening and any necessary next steps.
- Find a support group to discuss life changes, emotions, and strategies for coping with dementia.
- Complete a Healthcare Directive (also called a Living will or Advance Directive) regarding treatment preferences.

Complete a Durable Power of Attorney for Healthcare and appoint someone you trust to serve as a healthcare representative and assist with financial and related matters.

- Seek legal or financial advice if possible, or use free resources online or in the community to develop a financial plan and a will.
- Commit to stay active, eat well, and socialize as much as possible.
- Connect with the Rhode Island Chapter of the Alzheimer's Association and other experts for tools and free resources to manage medications, household chores, and daily responsibilities.
- Work with your healthcare provider to complete a Medical Orders for Life-Sustaining Treatment (MOLST) form.
- Secure a referral to a physical or occupational therapist for a home safety evaluation.
- Seek respite care, either in or outside of your home.
- Join a MedicAlert+Safe Return program.
- Look into residential care programs.
- Seek palliative services and/or hospice care and adjust or discontinue medications as appropriate.
- Ask for and accept support from other family members and friends, your faith community, volunteers, and other care providers.
- Review end-of-life arrangements.
- Consider grief counseling.





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