

VIRGINIA

Dementia Road Map:

A Guide for People Impacted by Dementia



VIRGINIA DEPARTMENT FOR AGING
AND REHABILITATIVE SERVICES



Virginia Dementia Road Map: A Guide for People Impacted by Dementia

CONTENTS

| | |
|--------------------------------------|-----|
| Overview..... | 2-6 |
| Wondering and Worried..... | 7 |
| Mild Cognitive Impairment (MCI)..... | 10 |
| Early-Stage Dementia..... | 13 |
| Mid-Stage Dementia..... | 17 |
| Late-Stage Dementia..... | 21 |
| Dementia Quick Reference..... | 23 |
| Palliative & Hospice..... | 25 |
| Communication Tips..... | 29 |
| Caring for the Care Partner..... | 31 |
| Resources..... | 33 |
| Action Steps Summary..... | 37 |

Virginia Dementia Road Map Overview



Wondering and Worried Page 7

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



Mild Cognitive Impairment (MCI) Page 10

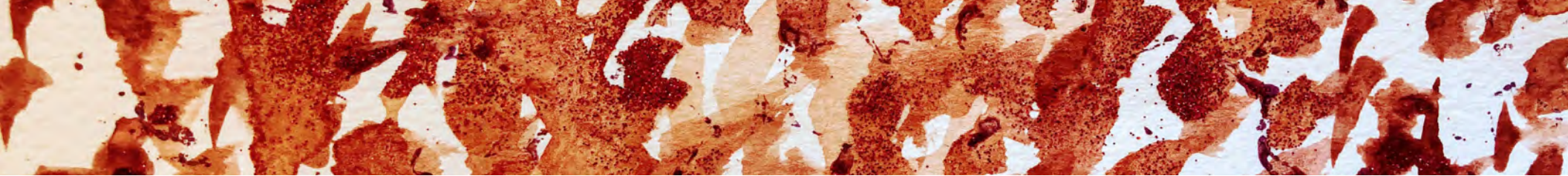
- Where do we go to get memory concerns checked out?
- How can I help my loved one with their memory and thinking?
- What can we do to promote our loved one's well-being?
- Can I share concerns privately with a health care professional?

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



Alzheimer's Disease and Related Disorders Commission





Early-Stage Dementia Page 13

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



Mid-Stage Dementia Page 17

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



Late-Stage Dementia Page 21

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



vda.virginia.gov/DementiaCapableVA.htm



easyaccess.virginia.gov



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Version with Links

This publication is illustrated with details taken from artworks created by people living with dementia participating in the Opening Minds Through Art program. See page 38 for more information on this program.



Virginia Dementia Road Map

For People Impacted by Dementia

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

Most families report they are not prepared for life with dementia and that they would welcome some type of “Road Map.” This document is designed to be just that. It provides a look at the big picture and the road ahead—and offers direction and tips about what to expect, what decisions lie ahead, and what steps to take. Although the *Guide* is largely from the perspective of someone providing support for the individual living with dementia, the information contained here may be useful for everyone impacted by dementia, including the individual themselves.

Research

Participating in research is a wonderful way to help speed advances in dementia treatment and care: Find out more at the Alzheimer’s Association’s TrialMatch by calling 800-272-3900 or ask your health care provider about clinical research opportunities.

Worried about memory loss in yourself or a loved one?

If you’re worried about forgetfulness, feel it’s getting worse or that the memory problems are starting to interfere with everyday life, it’s time to talk to a health care professional. Why is “getting checked” important? Because there are benefits to identifying and addressing memory loss, including:

- To find out what may be causing the problems—there are reasons for memory loss and confusion that are treatable. Some conditions that cause dementia, such as normal pressure hydrocephalus, thyroid problems or a vitamin deficiency, are treatable or reversible. Other conditions, such as depression or delirium, can seem like dementia. Even if it turns out to be a type of dementia, it’s best to get a diagnosis and help early in the disease process.
- A health care professional can provide better clinical care for all your medical conditions with a diagnosis, when they understand what is happening.
- You, your loved one and other family members can more easily plan for the future when you know what you are dealing with. A diagnosis makes taking the next steps a bit easier.
- If you live alone, visit nia.nih.gov/health/tips-living-alone-early-stage-dementia for tips and strategies.

Guides for the Journey


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

- Area Agencies on Aging (AAAs) are trusted sources of information and assistance, where older adults can turn to find specialized information, supports and service options in their area. They also offer caregiver support services that can assist family members as they are helping a loved one with dementia or other conditions. Find your local agency on p. 33, visit vda.virginia.gov/aaamap.htm or call 800-552-3402.
- The Alzheimer's Association has free literature on all things dementia available in English and Spanish, 24/7 phone support (in a caller's preferred language through a translation service), the latest information on brain health, available medications for people with dementia, support groups, trainings, and care consultation to help with decision-making, including useful guides for those with younger-onset Alzheimer's disease or another dementia. Visit www.alz.org or call 800-272-3900.
- There are other private supports and 'guides' such as geriatric care managers. You can learn about these by asking the information and referral specialists at your local Area Agency on Aging.
- Information on Memory Assessment Centers at: vda.virginia.gov/dementiacapableva.htm

Younger Onset Alzheimer's Disease

- Alzheimer's disease that appears in people under the age of 65 is called Younger Onset Alzheimer's Disease. Alzheimer's disease is often thought of something that only affects older people, but a small number of people show symptoms in their 40s and 50s or even younger. Other dementias may also appear in those under the age of 65, such as frontotemporal dementia. It is important to get any symptoms such as worsening memory loss or changes in personality checked by a health care professional.
- If you or your loved one are still working or raising a family, there are many things to consider with a diagnosis of younger-onset Alzheimer's disease. Visit youngdementianetwork.org/resources/resources-for-people-affected-by-young-onset-dementia for resources and information.
- The Social Security Administration (SSA) has added younger-onset Alzheimer's to the list of conditions under its Compassionate Allowance program, giving those with the disease expedited access to Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) ssa.gov
- Older American Act programs available through your local Area Agency on Aging were opened in 2020 to those caring for people diagnosed with Alzheimer's disease of any age. Contact your Area Agency on Aging for information on caregiver supports available.





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

- Dementia is a general term referring to a loss of cognitive function—remembering, thinking, and reasoning—severe enough to interfere with everyday life.
- Dementia is not a specific disease, but an overall term describing a wide range of symptoms. It is not normal aging. Dementia is caused by damage to the brain from disease or trauma.
- Alzheimer's disease is the most common cause of dementia. Other causes include vascular dementia, Lewy body dementia, and frontotemporal dementia.

Terminology:

Throughout this document, a variety of terminology is used:

- **Loved one**—this term refers to the person with memory loss or dementia
- **Care partner or family caregiver**—these terms refer to the person who is providing most of the support or care for their loved one.
- **Other friends and family**—this term refers to people other than the primary care partner who are concerned for their loved one with dementia and may provide assistance.
- **Respite Care**—Temporary relief for the primary caregiver through short-term care services (in-home or in a facility), allowing the caregiver time to rest, travel, or attend to other needs.

Am I a Caregiver?

While you may not think of yourself as a caregiver, these are things that caregivers typically do:

- Regularly help someone with tasks like bathing, dressing, eating, or taking medication.
- Drive or arrange transportation for someone to appointments or errands.
- Manage someone's finances, medications, or legal paperwork.
- Check in on someone daily to ensure their safety and well-being.
- Provide emotional support or advocacy for a loved one with memory loss or chronic illness.
- Help someone make decisions about their healthcare or daily routines.
- Coordinate care with doctors, home health aides, or other professionals.
- Feel responsible for another person's physical, mental, or emotional well-being.

Wondering and Worried



“Caregiving isn’t just about the feeding, the changing of clothing, the medical appointments. It’s about the special time you have with them. The one on one. It may not be a word spoken. It might just be holding hands. Let them feel your presence and your love.”

—Janie S.

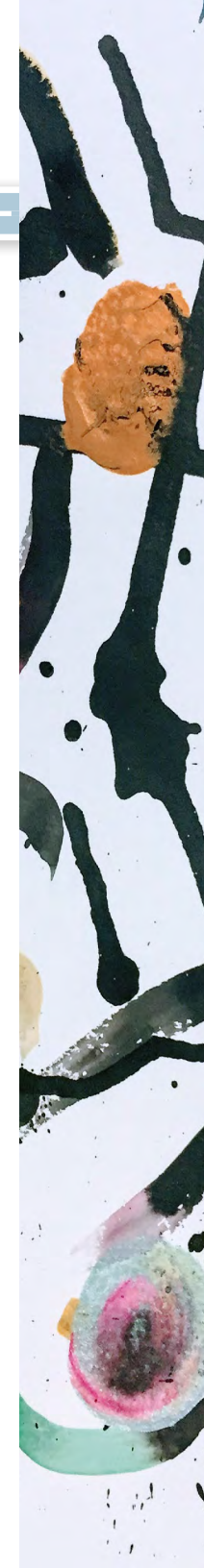
What should you expect in this stage?

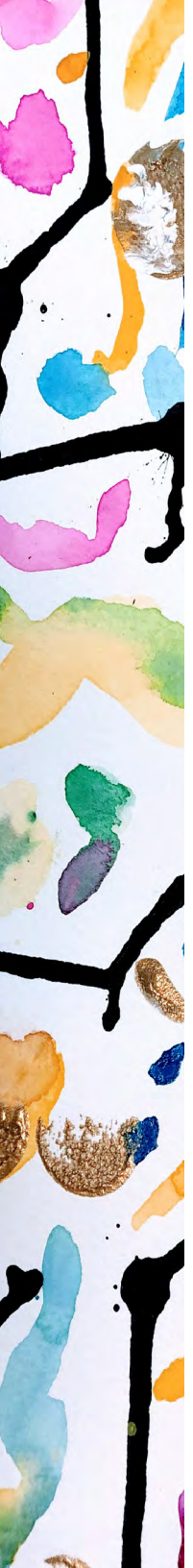
You notice changes in your own or your loved one’s memory, and thinking, but they may or may not affect daily life activities. For example, you may notice:

- Difficulty performing more than one task at a time.
- Difficulty solving complex problems or making decisions.
- Forgetting recent events or conversations.
- Taking longer to perform more difficult mental activities such as using the computer.
- Your loved one is likely concerned but may not discuss it. Other friends and family may or may not see or notice any changes.

You may be wondering

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





Wondering and Worried

What you can do:

- Learn about normal changes with aging and those that indicate a need to get a check up. See the “10 Warning Signs” on page 23.
- If you’re worried about changes in yourself, consider sharing your concerns with family, friends or your health care professional.
- Keep track of changes you notice. If your loved one doesn’t bring it up, find the right time and a sensitive way to discuss these changes with them—get it out in the open.
- Ask your loved one to have a complete medical check-up. It’s important to know if memory and thinking changes may be caused by something that could be treated or reversed. Even if not, it’s best to know what you’re dealing with.
- If your loved one is resistant to a medical check-up, enlist the help of trusted family or friends who may be able to encourage this.
- Call and ask your loved one’s health care professional for the Medicare Annual Wellness exam (if they are on Medicare) that includes detection of cognitive impairment along with other screenings. Feel free to share with the professional what you’ve noticed either in person or in a letter.
- If you don’t feel comfortable with your loved one’s current health care professional, try to find a new one. Many primary care professionals can diagnose dementia.

But if you’re looking for a specialist, contact the Alzheimer’s Association to help identify providers in your area or check for a Memory Assessment Center on the Dementia Capable Virginia website: vda.virginia.gov/dementiacapableva.htm

- Consider enrolling in a clinical trial or research study on dementia at a university or memory clinic. You and your loved one may advance our understanding of dementia and help in the effort to develop new treatments.
- If you know or suspect your loved one has hearing loss, get it checked and addressed—hearing loss makes it harder for a person with memory loss or confusion to communicate. This can lead to misunderstandings and social isolation.
- Make sure both you and your loved one are making healthy lifestyle choices:
 - Stay active and engaged in social groups, arts, and other activities of interest.
 - Eat fresh fruits and vegetables.
 - Be physically active.
 - Get plenty of sleep.
 - Try to minimize stress.Find out more: vdh.virginia.gov/brain-health/for-community-members
- Make it a priority to begin and/or complete legal, financial, and advance care planning, including essential planning documents. While all adults should have a plan in place in the event of disability or death, such planning is even more important for anyone beginning to experience changes in memory or thinking abilities. While such changes may or may not end up being dementia, it is critical to complete this planning while you or your loved one have the ability to do so.

ACTION STEPS

The following steps are important at this point:

- ❑ **Obtain a medical assessment** to find out what may be causing the problems.
- ❑ **Complete health care planning documents. You and your loved one should have:**
 - A Health Care Directive (also called a “living will” or “advance directive” regarding treatment preferences); and
 - A Durable Power of Attorney for Health Care, appointing a health care “agent.”
- ❑ **Complete a General Durable Power of Attorney document.** In this document, you/your loved one appoints an “agent” to assist with financial and related matters.
- ❑ **Complete an estate plan.** Your loved one’s estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- ❑ **Have a family meeting** to discuss what’s happening and necessary next steps.



Mild Cognitive Impairment (MCI)



“You look at everything your parents have done for you from the time you were born. My loyalties are so deep... God put me here. I feel so fortunate so blessed. I just want to take care of them the best I can.”

–Susan H. With her parents and her husband

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

What should you expect in this stage?

Your loved one is still independent but may have difficulty doing things like paying bills, preparing meals, shopping, and driving.

They may forget details, display less ambition, have emotions that go up and down, and be more reliant on you.

Your loved one may find particular success in completing familiar routines and habits.

You may:

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

You may be wondering

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

What you can do:

- If not yet evaluated, ask your loved one's health care professional for the Medicare Annual Wellness exam—it includes detection of cognitive impairment along with other screenings.
- Ask your loved one if you can attend and participate in their medical appointments, and to be included on a HIPAA or medical release form to access their health information.
- Inquire about lifestyle changes that may be helpful to overall wellness and functioning.
- Learn more about Mild Cognitive Impairment.
- Consider keeping a notebook about your loved one's changes and needs.
- Tell your own health care provider that you are caring for a loved one with cognitive impairment so they can be aware of potential health-related risks.
- Instead of thinking that your loved one should just “try harder”—remind yourself that they are doing the best they can.
- Be generous with your patience. Review the “Caregiver 10 Commandments” on page 32.
- Consider paying bills and shopping together so your loved one can have successes.

- Consider enrolling in a clinical trial or research study on dementia at a university or memory clinic. You and your loved one may advance our understanding of dementia and help in the effort to develop new treatments.
- Begin investigating Family and Medical Leave options and other respite services that can support you with caring for your loved one.

To help your loved one:

- Support them in managing any heart conditions, high blood pressure, high cholesterol, or diabetes as needed.
- Encourage a healthy lifestyle including regular exercise, a healthy diet, and social activities.
- Encourage the use of long-time skills, like playing the piano, singing, typing, crafts, or speaking a second language.
- Share (and read) the booklet—“Living Well with MCI or Early Dementia” from the Alzheimer's Association. See a link to this booklet in the Resource List on page 35.



Mild Cognitive Impairment (MCI)

ACTION STEPS

Remember! If your loved one has not yet had a medical assessment, contact their health care professional, a Geriatrician, a Neurologist, and/or a Neuropsychologist.

- Discuss with your loved one** the issue of when to discontinue driving.
- Complete health care planning documents. You and your loved one should have:**
 - A Health Care Directive (also called a “living will” or “advance directive” regarding treatment preferences); and
 - A Durable Power of Attorney for Health Care, appointing a health care “agent.”
- Complete a General Durable Power of Attorney document.** In this document, you/your loved one appoints an “agent” to assist with financial and related matters.
- Complete an estate plan.** Your loved one’s estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- Encourage other family and friends** to visit regularly.
- Have a family meeting** to discuss what’s happening and necessary next steps.

Early-Stage Dementia



“Starting off...a lot of things are trial and error. You’re learning to take care of a person, and meet their needs, and it’s a little more difficult when a person who has dementia or Alzheimer’s can’t explain to you what their needs are. So, you have to be observant, and watch them and then attend to them as needed.”—Vivian J.

You may be wondering

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





Early-Stage Dementia

What should you expect in this stage?

Your loved one has difficulty accomplishing some activities.

They may also:

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

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

You may:

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

What you can do:

- Be an advocate for the right diagnosis and best health care. If you're not happy with current care, find a health care professional that will work with you and your loved one together.
- Talk to a pharmacist or health care professional about safe medication management strategies.
- Learn all you can about the disease and tips for communicating supportively with your loved one. See Communication Tips on page 29.
- Put safety measures in place before they're needed related to falls, wandering, medication use, harmful cleaning products, guns, power tools, etc. Find information on safety in the Resource List on page 33.
- Embrace the good days and prepare yourself for the stormy ones.
- Make your life a no guilt zone.
- Keep up health and wellness appointments for yourself.
- Make efforts to get a good night's sleep every night.
- Seek out support and reassurance: talk with others who have had a similar situation (e.g., early memory loss support group) or call the Alzheimer's Association Helpline at 800-272-3900.
- Explore how your loved one wants to live at the end of their life. Learn about "having the conversation", through the "Conversation Starter Kit for Families of Loved Ones of People with Alzheimer's Disease or other Forms of Dementia." See Resource List on page 33.
- Encourage your loved one to use the in-depth dementia advance planning legal document, "Alzheimer's and Dementia Mental Health Advance Directive" to document their wishes about anticipated challenges throughout the progression of the disease (such as when to stop driving, where they want to live, who provides their care). See Resource List on page 33.

To help your loved one:

- Provide “Living with Alzheimer’s: Taking Action Workbook.” Find this in the Resource List on page 33.
- Go along on medical appointments if your loved one agrees. If they do not want this, try calling the practitioner ahead of appointments to share concerns.
- Create and stick to simple routines.
- Monitor that any medications are taken properly.
- Assist them to continue activities of interest.
- Promote the best functioning possible. Get hearing loss and vision checked regularly. Make sure hearing aids and glasses are in good condition and used as needed.
- Resist the urge to step in and do things for them; allow more time, and occasional errors.
- Encourage them to attend an early stage support group and seek out dementia-friendly recreation activities.
- Consider enrolling in a clinical trial or research study on dementia at a university or memory clinic. You and your loved one may advance our understanding of dementia and help in the effort to develop new treatments.
- When you see behaviors that are “out of character,” do NOT take these personally—recognize it’s the disease.
- Look for ways to modify your loved one’s favorite activities rather than give them up.
- Help family and friends understand how to communicate and interact—if needed you can share what they like to do, how to start a conversation, the need to avoid correcting and arguing.

Consider ways to protect yourself and your loved one from financial missteps and exploitation such as removing your loved one’s credit cards (or lower credit limits) and other key wallet documents.

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

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

Area Agency on Aging for your area may be found on page 33, or at 800-552-3402 or vda.virginia.gov/aaamap.htm

Alzheimer’s Association at 800-272-3900 or www.alz.org.

Services to consider:

- Educational workshops
- Dealing with Dementia workshop for caregivers
- Alzheimer’s/dementia seminars
- E-Learning and Online courses
- Virginia Navigator’s Virginia Family Caregiver Solution Center at vf.virginiannavigator.org
- Get connected Online—try the Alzheimer’s Navigator, ALZConnected Online community or e-learning modules offered through the Alzheimer’s Association and/or the “Alzheimer’s Reading Room.”
- The Alzheimer’s Association collaborates with MedicAlert to provide 24/7 Wandering Support using a community support network including the police to locate your loved one in case they wander.
- Consultants who specialize in caregiving and/or dementia may be available. Check with your local Area Agency on Aging or the Alzheimer’s Association.



Early-Stage Dementia

ACTION STEPS

See Action Steps on pages 9 and 12, and do the following:

- **If your loved one** is still driving, review together the booklet “At the Crossroads: Family Conversations about Alzheimer’s, Dementia and Driving” which may be found in the Resource List on page 33, and consider an objective driving evaluation with a certified driving rehabilitation specialist.
- **Make sure your loved one** either carries ID or wears MedicAlert+Safe Return jewelry.
- **Discuss with your loved one** their wishes for end-of-life care, and document these as decisions are made.
- **Explore palliative care options** see pages 25-28.
- **Have a family meeting** to discuss what’s happening and next steps, such as ways the family can support the person with memory loss to stay active, healthy and socially engaged, or help you with decisions and planning around driving or other safety concerns.
- **Make a back-up plan** to be used if something happens to you. Write it down and share it with the family.
- **Consider Care Coordination or Case Management Services:** “Guides” for the journey, they can assist with each step. See more on page 5.
- **Contact the Alzheimer’s Association** for dementia-related information, education and support opportunities.
- **Contact your local Area Agency on Aging** to find out more about local support services.

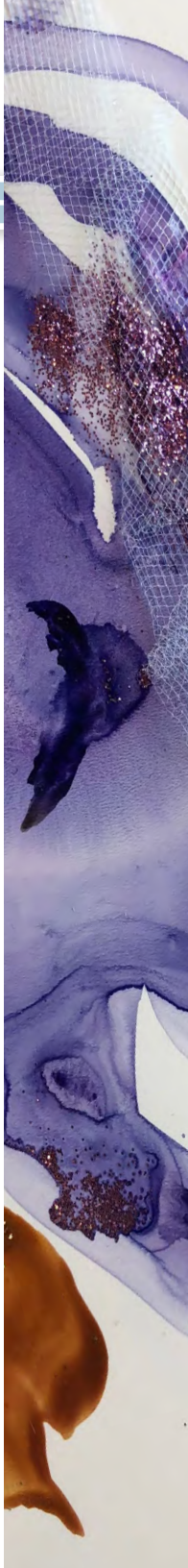
Mid-Stage Dementia



Tim's father asked, "What are you talking about?" "We are talking about taking care of you 'cause you took care of us for so long. You take care of yourself...we just give you a little bit of assistance." —Timothy J.

You may be wondering

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





Mid-Stage Dementia

What should you expect in this stage?

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

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

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

You may:

- Feel tired, stressed, lonely, isolated, angry, or irritable.
- Be wondering if you need assistance, or how long you can do this.
- Notice that other friends and family are wondering how to help, sometimes wanting to take over the care. Be open to offering some direction on how they can best help you or your loved one.

What you can do:

- At this stage, you will need the following kinds of support:
 - Daily relief from care tasks (sometimes known as Respite Care)
 - A network of caring friends and family
 - Time to manage your own self-care
- Establish or maintain routines for you and your loved one.
- Try not to mistake loved one's moodiness for rudeness.
- Practice not taking behaviors personally—it's the disease.
- Ask for help with taking care of the home or providing care: housekeeping, errands, yard care, handy person, or in-home assistance for your loved one.
- If you get unwanted opinions or criticisms, take a step back and recognize that others may be trying to help—see if you can work out a plan for them to assist in some way. Recognize that you are doing the best you can.
- Attend a support group.
- Vent as needed with trusted friends or other caregivers.
- Take safety precautions related to falls, wandering, medication use, harmful cleaning products, guns, power tools, etc.
- If your loved one is still driving, enlist the help of their health care provider to get them to stop. Call the Alzheimer's Association for additional ideas.

- Consider enrolling in a clinical trial or research study on dementia at a university or memory clinic. You and your loved one may advance our understanding of dementia and help in the effort to develop new treatments.
- Look into support and service options to help maintain current living arrangement, such as in-home care or adult day services.
- Investigate residential care options in your area in the event they are needed in the future. These might include adult family homes, assisted living, and/or nursing homes. Look into their costs and take tours so you'll be prepared if you need to make a decision quickly.

To help your loved one:

- Encourage family and close friends to learn communication tips and techniques—and to help provide activities your loved one still enjoys. Refer them to the Alzheimer's Association website or 24/7 toll-free Helpline: 800-272-3900.
- Try to provide kindness, understanding, and acceptance.
- Channel their energy—go for regular walks together, encourage them to help with chores like vacuuming, sweeping, folding laundry, gardening.
- Simplify tasks and activities, break into smaller steps—allow more time for your loved one to accomplish them.
- Reminisce—look at old photo albums, a memory book or old videos.
- Make sure your loved one gets ongoing medical care.
- If you notice any SUDDEN changes in behavior, call your loved one's physician—this can be a sign of an infection or other medical issue.
- Talk to their doctor about completing a Physician Order for Scope of Treatment (POST) form, and ask for a referral to a Physical or Occupational Therapist for a home safety evaluation.

- Go to the Alzheimer's Association's Online "Caregiver Center" to find helpful tips on daily care such as activities, providing personal care and managing incontinence. Visit www.alz.org/help-support/caregiving to learn more.

Services to consider

- Education workshops or conferences for caregivers.
- Technology to assist with a variety of tasks—reminders, cameras, chimes to alert if an exterior door opens, etc.
- Adult day services offer your loved one activity, exercise and socialization and provides you with some time for yourself.
- In-home care to assist with bathing, dressing, getting ready in the morning or evening, other personal care tasks/routines.
- Counseling to handle your own grief, depression and anger, and get emotional support.
- If you haven't looked into or used yet:
 - Dealing with Dementia workshop for caregivers
 - Support Group
 - Respite Care (in or out of the home)
 - Consultants who specialize in caregiving issues and can assist with dementia-related behaviors
 - MedicAlert+Safe Return or GPS locator program
 - Behavior education and consultation

Contact your local Area Agency on Aging to inquire about local education and support services mentioned above. Find your local agency on pages 33-34.





Mid-Stage Dementia

ACTION STEPS

See Action Steps on pages 9, 12 and 16, and do the following:

- ❑ **Request a home safety evaluation** with a Physical or Occupational Therapist to make the home safer and home care tasks easier.
- ❑ **Update your back-up plan** to be used if something happens to you.
- ❑ **Have a family meeting** to discuss what's happening now and ways to support your loved one and you, and any next steps as care needs increase.
- ❑ **Explore palliative care options** see pages 25-28.
- ❑ **If help with financing care** is needed, contact your local Area Agency on Aging. You can find their details on p. 33 or at vda.virginia.gov/aaamap.htm
- ❑ **Complete end-of-life planning.** Discuss and document how your loved one wants to live at the end of their life, including medical care wanted or not wanted, comfort measures, and palliative and hospice care.

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

- Find out more about the services listed on p. 19, and what may be available at no cost or low cost in your area.
- Area Agency on Aging for your area may be found on p. 33 or at 800-552-3402 or vda.virginia.gov/aaamap.htm .
- Alzheimer’s Association at 800-272-3900 or www.alz.org
- Find out more, and what’s available in your area, by visiting easyaccess.virginia.gov .

Want to learn more about residential care options?

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

Late-Stage Dementia



"I always tell him I love him and I try to hug him. And sometimes he'll put his hand up on my cheek and just say, "You're so pretty" or "I love you" or something. It touches my heart. (Stops to cry.) When we sing together, it's sweet." –Leslie P.

You may be wondering:

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

You may feel like this:

"I'm worn out and I am grieving."

- Reach out to others in a similar situation, a care coordinator, a counselor, the Alzheimer's Association or your local Area Agency on Aging for support.
- Area Agency on Aging for your area may be found on p. 33 or at 800-552-3402 or vda.virginia.gov/aaamap.htm
- Alzheimer's Association at 800-272-3900 or www.alz.org





Late-Stage Dementia

What should you expect in this stage?

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

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

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

You may:

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

What you can do:

- Be gentle with yourself and your loved one. Respect yourself for the love and support you have provided for your loved one and yourself.
- Allow plenty of time for tasks and activities—don't rush.

- Be together in ways that don't require words.
- Actively seek palliative care and/or hospice care (see page 25).
- Review with your loved one's health care professional any health issues and their related medications that could be reduced or discontinued.
- Consider what kind of emotional support you may want or need during the period near and after death.
- Attend a support group.
- Consider including your closest friends and family in discussions about the end-of-life preferences and plans that have already been made.

To help your loved one:

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

Services to consider:

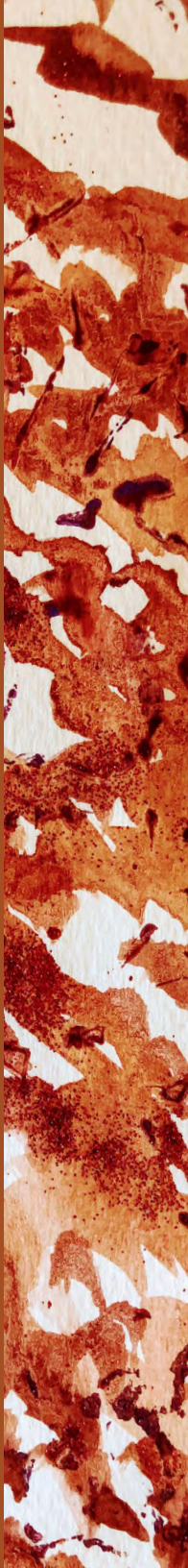
- In-home or residential care
- Palliative care and hospice care (see pages 25-28)
- Support group
- Counseling or other emotional support for yourself

Dementia Quick Reference

10 Warning Signs of Alzheimer's

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

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





Early-Stage Dementia

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

Mid-Stage Dementia

- Increasing needs for care and supervision.
- More trouble with memory—such as own address or personal history.
- Problems organizing, planning, allowing instructions and solving problems.
- Not recognizing familiar people.
- Difficulties with reading, language and communication.
- Forgetting how to initiate or complete tasks, including health and hygiene care.
- May resist bathing or other personal care.
- Abilities that vary from one day to the next.
- May complain of neglect or blame others when things go wrong.
- Lacking judgment and developing the following behaviors: trouble sleeping, apathy, passivity, irritability, aggressive talk and actions, clinging (following you around), repetitive questions, wandering.
- Delusions (false beliefs) or hallucinations (seeing/hearing things that aren't there).
- More problems with balance (increasing the risk for falls).
- Not being able to contribute to family life in traditional ways.

Late-Stage Dementia

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

Understanding Palliative Care and Hospice Services



“I watched her do it for so long, it’s become part of my daily life. She did it for her dad, and I feel like I have to do it for her. Being at home, being around family, it has sustained her.” -Michelle H.

When someone you love has dementia, it can be challenging to know how to support them as the disease progresses. Two important types of care, **palliative care** and **hospice services**, can make a big difference in their quality of life. Understanding these services can help you make the best choices for your loved one.

What is Palliative Care?

Palliative care focuses on improving the quality of life for people with serious illnesses like dementia. It helps manage symptoms, reduce stress, and provide emotional and spiritual support. This type of care can start at any stage of dementia, even early on, and can be given alongside other treatments.

Palliative care teams usually include doctors, nurses, social workers, and sometimes chaplains. They work together to treat symptoms like pain, trouble sleeping, anxiety, or difficulty eating. They also help families cope with the emotional toll of dementia.

For example, if your loved one is having trouble swallowing, the palliative care team might suggest foods that are easier to eat or help create a feeding plan. If they are feeling anxious or confused, the team might offer medicines or calming techniques to help them relax.

Palliative care can take place in different settings, such as at home, in a hospital, or in a care facility. The goal is to make your loved one feel as comfortable and supported as possible.



Understanding Palliative Care and Hospice Services

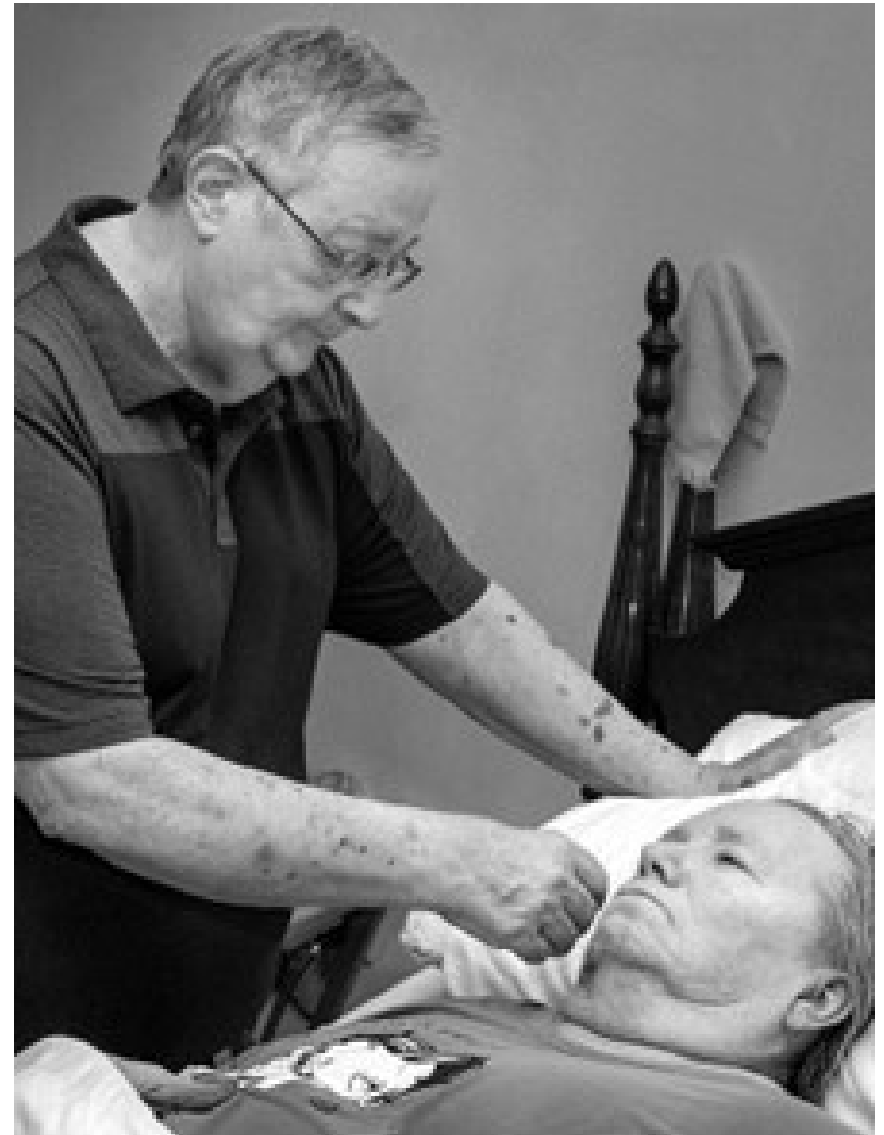
What is Hospice Care?

Hospice care is for people who are in the final stages of a terminal illness, including advanced dementia. This care is focused on comfort, not curing the disease. Hospice typically begins when a doctor believes the person has about six months or less to live.

Hospice teams also include doctors, nurses, social workers, chaplains, and volunteers. They provide physical, emotional, and spiritual support to both the person with dementia and their family. Services can include managing pain, preventing discomfort, and helping families make tough decisions.

For people with advanced dementia, hospice care might involve ensuring they are not in pain, helping with feeding and bathing, or simply sitting with them to provide companionship. The team can also guide families on how to communicate with their loved one as verbal skills decline.

Hospice care usually happens at home or in a hospice facility. It allows people with dementia to spend their final days in a peaceful, supportive environment, surrounded by loved ones.



Understanding Palliative Care and Hospice Services

You may be wondering

- How can palliative care and hospice services help?
- When is the right time to ask about these services?
- Where can I learn about palliative and hospice care?
- How can I pay for these services?

“Respite at hospice house has been offered. I don’t want to be away from her...I made a promise I would never put her in a nursing home. I’ve hired [in-home hospice] help to assist with her care.” -Clyde J. (pictured left)

Palliative and hospice care resources:

- **National Institute on Aging:** www.nia.nih.gov/health/hospice-and-palliative-care
- **Alzheimer’s Association:** www.alz.org/help-support/caregiving/care-options/hospice-care

How these services help families:

Caring for someone with dementia can be overwhelming. Palliative and hospice care provide support not just for the person with dementia but also for their caregivers. These services can help you navigate difficult decisions, offer grief counseling, and connect you with resources like respite care so you can take a break when needed.

When to ask about these services:

It’s never too early to ask about palliative care. Starting sooner can improve the quality of life for your loved one and give your family more time to plan for the future. Hospice care is typically introduced later, but talking to your doctor early on can help you prepare.

Remember, you’re not alone. These services exist to support you and your loved one through every step of the journey with dementia.



Understanding Palliative Care and Hospice Services

Paying for palliative or hospice care in Virginia depends on your situation and what kind of insurance you have.

What you can do:

- **Check Your Insurance:** Contact your insurance provider to see what services are covered and what you may have to pay.
- **Talk to the Hospice Provider:** Hospice agencies often have people who can help you understand your payment options and assist with insurance or funding.

Talking to someone at the hospice care center can help you figure out the best way to pay for the care you need. Your local Area Agency on Aging (see p. 29) can help connect you with local hospice providers.

Here are some common ways to pay:

Medicare: Medicare Part A usually pays for hospice care, including doctor visits, nursing care, pain relief, and medications. To qualify, you must have a terminal illness and expect to live for 6 months or less. Medicare covers most of the costs, but you might have to pay a small amount for some medications and respite care

Medicaid: Medicaid usually covers hospice services, including medical care and support for the patient and family. Most people on Medicaid will not need to pay anything for hospice care, but some small fees may apply for certain services.

Private Insurance: Private insurance may cover hospice care the same way Medicare does, but the details can vary. You may have to pay a co-pay or deductible, depending on your insurance plan.

Veterans Affairs (VA) Benefits: The VA provides hospice care, including medical treatment, pain management, and support services. Most of the care is free, but there could be small costs for certain services.

Out-of-Pocket: The cost can vary depending on the type of care and where it's provided. This can be expensive, but some hospice programs may offer payment plans or lower fees based on your financial situation.

Charity and Community Help: Some hospices provide financial help or work with organizations that can assist with costs. You may be able to get some help paying for care, especially if you are having financial trouble.

Communication Tips



“People fall off when there is something chronic. That’s the way it is. One man, whom we did not know years ago, came up to Bill and said, ‘I think you need a friend and I need one too.’ They told the same stories back and forth so much that if one forgets what he was going to say, the other can fill in.” Bill agrees and laughs. –Caroline M.

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

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

Communication Tips

What you can do:

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

It's important to remember that your loved one isn't trying to be difficult—the disease has changed their brain. Try your best not to take communications and behaviors personally.

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

Caring for the Care Partner



“My daughters, they kept saying, ‘Mom, you need to get some help to come in to help you.’ And I was like, ‘I’m okay. I’m okay, right now.’ But last month, two... three weeks now, I did seek, help. And that gives me a chance to go out. Run errands and whatever.

As a matter of fact, I went to a movie Saturday evening. It was awesome.”

—Rosie H.

Caring for yourself is one of the most important things you can do as a care provider for your loved one. When your needs are taken care of, your loved one will benefit too. You can do this by asking family members or friends to help out, taking time to do things you enjoy, using respite services such as adult day programs, or getting help from a home health care agency. Taking these actions may provide you with relief and can help prevent you from getting ill or depressed. Since the Covid-19 pandemic, many more services and supports are available virtually, such as virtual support groups, potentially giving you more options. Contact the agencies and referral sources on the next pages for more information.

Remember this affirmation on your journey: *I care for myself so that I can continue caring for my loved one. I am doing my best, that is enough.*



What you can do:

- Make some time for self-care. Keep up with your own doctor appointments and try to get enough sleep. Drink water and eat nourishing meals. Stretch or walk around the block. Take time—even a few minutes—to do something for yourself. Find more ways to keep yourself healthy here www.alz.org/help-support/caregiving/caregiver-health
- Join a caregiver support group. Support groups are a chance to share your story and learn from others in similar situations. Contact your local Area Agency on Aging or the Alzheimer's Association to find a support group near you or a virtual support group.
- Learn new caring skills. Learning more about dementia can ease stress and help you provide better care for your loved one. Contact your local Area Agency on Aging, the Alzheimer's Association, or access the Riverside Health Caring for You, Mind, Body and Soul modules.
- Learn about available resources and supports. Get a copy of *Taking Care: A Resource Guide for Caregivers* created by the Virginia Caregiver Coalition on vda.virginia.gov/vcc.htm, contact your local Area Agency on Aging or the Alzheimer's Association.

Caregiver Wellness Check-In

- Am I sleeping at least six hours per night?
- When did I last eat a full meal?
- Have I done something for myself this week?
- Do I feel supported?

Caregiver 10 Commandments

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

Resources

GENERAL ASSISTANCE AND REFERRALS

| | |
|--|---------------------|
| Virginia 2-1-1 | 211 |
| Department for Aging and Rehabilitative Services | 800-552-3042 |
| Alzheimer’s Association 24/7 | 800-272-3900 |
| Helpline Alzheimer’s and related Dementias Education and Referral Center (ADEAR Center)... | 800-438-4380 |
| DARS Dementia Services | 804-662-9154 |

VIRGINIA’S NETWORK OF AREA AGENCIES ON AGING

| Agency Name/Website | Counties/Cities Served | Phone Number |
|--|---|------------------------------|
| Alexandria Division of Aging and Adult Services www.alexandriava.gov/Aging | Alexandria | 703-746-5999 |
| Appalachian Agency for Senior Citizens www.aasc.org/ | Buchanan, Dickenson, Russell, Tazewell | 276-964-4215 800-656-2272 |
| Arlington Agency on Aging www.arlingtonva.us/Government/Departments/DHS/Aging-Disability/Area-Agency-Aging | Arlington | 703-228-1700 |
| Bay Aging bayaging.org/ | Essex, Gloucester, King and Queen, King William, Lancaster, Mathews, Middlesex, Northumberland, Richmond (County), Westmoreland | 804-758-2386 |
| Central Virginia Alliance for Community Living (CVACL) www.cvacl.org/ | Amherst, Appomattox, Bedford, Campbell, Lynchburg | 434-385-9070 |
| Crater District Area Agency on Aging cdaaa.org/ | Colonial Heights, Dinwiddie, Emporia, Greensville, Hopewell, Petersburg, Prince George, Surry, Sussex | 804-732-7020 |
| District Three Governmental Cooperative district-three.org/ | Bland, Bristol, Carroll, Galaz, Grayson, Smyth, Washington, Wythe | 276-783-8157 800-541-0933 |
| Eastern Shore Area Agency on Aging/Community Action Agency www.esaaa-caa.net/ | Accomack, Northampton | 757-442-9652 800-452-5977 |
| Encompass Community Supports www.encompasscommunitysupports.org/ | Culpeper, Fauquier, Madison, Orange, Rappahannock | 540-825-3100 |

VIRGINIA'S NETWORK OF AREA AGENCIES ON AGING

| Agency Name/Website | Counties/Cities Served | Phone Number |
|--|---|------------------------------|
| Fairfax Department of Family Services—Older Adults www.fairfaxcounty.gov/familyservices/older-adults | Fairfax (City/County), Falls Church | 703-324-7948 |
| Healthy Generations Area Agency on Aging healthygenerations.org/ | Caroline, Fredericksburg, King George, Spotsylvania, Stafford | 540-371-3375 |
| Jefferson Area Board for Aging (JABA) www.jabacares.org/ | Albemarle, Charlottesville, Fluvanna, Greene, Louisa, Nelson | 434-817-5222 |
| Lake Country Area Agency on Aging lcaaa.org/ | Brunswick, Halifax, Mecklenburg | 434-447-7661 800-252-4464 |
| Local Office on Aging (LOA) loaa.org/ | Alleghany, Botetourt, Covington, Craig, Roanoke (City/County), Salem | 540-345-0451 |
| Loudoun County Area Agency on Aging www.loudoun.gov/4919/About-the-Area-Agency-on-Aging | Loudoun | 703-777-0257 |
| Mountain Empire Older Citizens meoc.org/ | Lee, Norton, Scott, Wise | 276-523-4202 800-252-6362 |
| New River Valley Agency on Aging www.nrvaooa.org/ | Floyd, Giles, Montgomery, Pulaski, Radford | 540-980-7720 866-260-7724 |
| Peninsula Agency on Aging paainc.org/ | Hampton, James City, Newport News, Poquoson, Williamsburg, York | 757-873-0541 |
| Piedmont Senior Resources Area Agency on Aging psraaa.org/ | Amelia, Buckingham, Charlotte, Cumberland, Lunenburg, Nottoway, Prince Edward | 434-767-5588 800-995-6918 |
| Prince William Area Agency on Aging www.pwcva.gov/department/area-agency-aging | Prince William, Manassas, Manassas Park | 703-792-6374 |
| Senior Services of Southeastern Virginia www.sseva.org/ | Chesapeake, Franklin, Isle of Wight, Norfolk, Portsmouth, Southampton, Suffolk, Virginia Beach | 757-461-9481 |
| Seniors First, The Shenandoah Area Agency on Aging seniorsfirst.info/ | Clarke, Frederick, Page, Shenandoah, Warren, Winchester | 540-635-7141 |
| Southern Area Agency on Aging www.southernaaa.org/ | Danville, Franklin, Henry, Martinsville, Patrick, Pittsylvania | 276-632-6442 800-468-4571 |
| The Span Center spancenter.org/ | Charles City, Chesterfield, Goochland, Hanover, Henrico, New Kent, Powhatan, Richmond (City) | 804-343-3000 |
| Valley Program for Aging Services vpas.info/ | Augusta, Bath, Buena Vista, Harrisonburg, Highland, Lexington, Rockbridge, Rockingham, Staunton, Waynesboro | 540-949-7141 800-868-8727 |

Resources

ORGANIZATIONAL WEBSITES

- Alzheimer's Association: www.alz.org or 800-272-3900
- Adult Day Programs: www.dss.virginia.gov/facility/search/adc.cgi
- Assisted Living facilities: www.dss.virginia.gov/facility/search/alf.cgi
- Area Agency on Aging: vda.virginia.gov/aaamap.htm or 800-552-3402
- Eldercare Locator (US Administration on Aging): eldercare.acl.gov or 800-677-1116
- Virginia Association for Hospices & Palliative Care: <https://www.vahc.org/>
- Virginia Memory Project, Virginia's Alzheimer's disease and dementia registry and pathway to care: vcoa.chp.vcu.edu/initiatives/va-memory-project/

INFORMATION AND DOCUMENTS

- At the Crossroads: Family Conversations about Alzheimer's, Dementia and Driving and other resources on dementia and driving: thehartford.com/resources/mature-market-excellence/dementia-driving
- Virginia Grand Driver: Provides Virginians with information and resources about staying safe and mobile on the road. www.granddriver.net
- Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging and other dementia-related publications in English and Spanish: order.nia.nih.gov/publication/caring-for-a-person-with-alzheimers-disease-your-easy-to-use-guide
- Communication: Tips for Successful Communication During All Stages of Alzheimer's Disease: www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/how-to-communicate-dementia
- Dementia and Driving Issues: www.alz.org/care/alzheimers-dementia-and-driving.asp
- Home Safety for People with Alzheimer's Disease: <https://www.alz.org/help-support/caregiving/safety/home-safety>
- Living Well with MCI or Early Dementia: www.actonalz.org/pdf/Living-Well.pdf
- Living with Alzheimer's—Taking Action Workbook: www.alz.org/getmedia/da9e2ce1-d73c-437a-be7c-d5761afd06e9/taking-action-workbook
- Safety Concerns for People with Dementia—An Info Kit: vda.virginia.gov/dementiacapableva.htm

Resources

RESOURCES FOR LEGAL AND ADVANCED CARE PLANNING

- Conversation Starter Kit For Families and Loved Ones of People with Alzheimer’s Disease or Other Forms of Dementia— To help people with dementia have conversations with their family members about how they want to live at the end of their lives —about the care they want, and the care they don’t want. It is designed to be used in the early stages of dementia. theconversationproject.org/get-started .
- Virginia Advance Directives—Offers information on advance directives related to mental health and other conditions such as dementia, forms and resources: www.virginiaadvancedirectives.org.
- Honoring Choices Virginia—Offers information, tools and resources for various end-of-life choices: www.honoringchoices-va.org.
- Virginia Legal Aid—Offers free information and resources for Powers of Attorney, Advance Directives and other elder law topics: www.valegalaid.org/issues/elder-law.
- Virginia Poverty Law Center—Offers links to referral services: vplc.org/learn/resources/ .

RESOURCES ON OTHER DEMENTIAS

- Alzheimer’s Disease and Related Dementias, National Institute on Aging and the Alzheimer’s and related Dementias Education and Referral Center (ADEAR): www.nia.nih.gov/health/alzheimers or 800-438-4380
- The Association for Frontotemporal Degeneration: www.theaftd.org
- Frontotemporal Disorders: Information for Patients, Families and Caregivers: catalog.ninds.nih.gov/ninds/product/Frontotemporal-Disorders-Information-for-Patients-Families-and-Caregivers/19-AG-6361
- Lewy Body Dementia Association: www.lbda.org
- Lewy Body Dementia—Information for Patients, Families and Caregivers: catalog.ninds.nih.gov/ninds/product/Lewy-Body-Dementia-Information-for-Patients-Families-and-Professionals/18-AG-7907
- Vascular contributions to cognitive impairment and dementia: www.nia.nih.gov/health/vascular-contributions-cognitive-impairment-and-dementia

ACTION STEPS SUMMARY

- **Obtain a medical assessment** of memory loss/cognitive impairment and diagnosis for your loved one—this opens the door to necessary planning. This process should start with your health care practitioner, and may involve other specialists such as a Geriatrician, a Neurologist, and/or a Neuropsychologist.
- **Contact the Alzheimer’s Association** for information and support.
- **Contact your local Area Agency on Aging (page 33).**
- **Complete health care planning documents.** Your loved one should have:
 - A Health Care Directive (also called a “living will” or “advance directive” regarding treatment preferences); and
 - A Durable Power of Attorney for Health Care, appointing a health care “agent.”
- **Complete a General Durable Power of Attorney document.** In this document, your loved one appoints an “agent” to assist with financial and related matters.
- **Complete an estate plan.** Your loved one’s estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- **Consider Care Coordination** or Case Management Services: “Guides” for the journey, they can assist with each step.
- **Complete end-of-life planning** and document how your loved one wants to live at the end of their life, including medical care wanted or not wanted, comfort measures, and palliative and hospice care.
- **Discuss with loved one the issue of when to discontinue driving.** If needed, enlist help of healthcare provider, a professional driving evaluation, or call the Alzheimer’s Association for more ideas.
- **Make sure your loved one either carries ID** or wears MedicAlert+Safe Return jewelry.
- **If help with financing care is needed,** contact your local Area Agency on Aging. Find these on page 33 or at vda.virginia.gov/aaamap.htm.
- **Have family meetings** along the way to discuss what’s happening, and how to support the person with memory loss and care partner. Important topics of discussion include:
 - Encouraging a diagnosis;
 - Discussing safety issues, such as driving and safe medication use;
 - Needing support with financial or legal planning;
 - Coordinating care at home;
 - Considering safe living situation and options;
 - Discussing ways to support the primary care partner/caregiver.
- **Request a home safety evaluation** with a Physical or Occupational Therapist to make the home safer and home care tasks easier.
- **Make and update a back-up plan** along the way to be used if something happens to you.
- **Discuss and seek palliative care** and hospice care. See pages 25-28.
- **Talk to health care professional** about establishing a Physician’s Order for Scope of Treatment (POST) when appropriate.

Virginia Alzheimer’s Disease and Related Disorders Commission

The Alzheimer’s Disease and Related Disorders Commission was established in 1982 to advise the Governor and the General Assembly on policy, funding, regulatory and other matters relating to Alzheimer’s disease and dementia. It is charged with developing Virginia’s state plan for dementia and examining ways the Commonwealth can most effectively and efficiently help meet the needs of people living with dementia and their care partners. You can learn more about the Commission on vda.virginia.gov/boardsandcouncils.htm.

Virginia’s first Dementia State Plan was published in 2011 to lay the groundwork for statewide dementia capability. The Plan was updated and expanded in 2015, 2019 and 2024 and provides a blueprint for a fully dementia capable and dementia friendly state. The Dementia Road Map supports the achievement of Goal IIIB of the Dementia State Plan 2024-2027. The Plan can be found on vda.virginia.gov/dementia.htm

The Commission would like to acknowledge the work of Washington State’s Dementia Action Collaborative in developing this Dementia Road Map, and offers its gratitude to the Dementia Action Collaborative for permitting the Commission to adapt this resource to support Virginians learning to live with Alzheimer’s disease or another dementia.

The Coordinated Care Workgroup of the Commission drove the Road Map adaptation. Its members were Khurrum Khan, Chair, Laura Bowser, Karen Darner, Fonda Neal and Tina Thomas, supported by the DARS Dementia Services Coordinator, George Worthington. The Commission would like to thank the Alzheimer’s Association, the Department for Aging and Rehabilitative Services, the Virginia Department of Health and Virginia’s Area Agencies on Aging for their collaboration in helping make this resource a reality.

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The Commission is extremely grateful to Cindy Paullin for permission to use artwork created by people living with dementia. The Art for the Journey “Opening Minds Through Art” (OMA) program is a best practice art program designed to promote well-being for people with dementia. Developed by Dr. Elizabeth Lokon, a gerontologist at Miami University-Ohio, the OMA program builds bridges over age and cognitive barriers by pairing elders with college age or community volunteers in a person-centered experience creating abstract art. In the OMA program, volunteers are trained to focus on the resident’s strengths, rather than lost skills. Art for the Journey facilitates the OMA program in facilities in assisted-living residence partners in Richmond, VA, and also provides an **OMA Facilitator certification training course** in partnership with Dr. Lokon, to certify others to facilitate OMA in other locations. For more information about OMA Facilitator certification or OMA volunteer trainings near you, please contact Cindy Paullin, Executive Director - Art for the Journey at: cindy@artforthejourney.org. Visit Art for the Journey at: artforthejourney.org.



You can find this publication online:
vda.virginia.gov/DementiaCapableVa.htm.

If you are interested in a paper copy for yourself or are an organization wanting to share these directly with individuals or families who may benefit, you may request a limited number of copies at the email below by providing your name, organization, street shipping address and the quantity desired.

This publication was updated in 2025; we welcome your feedback.

To order paper copies:
dementia@dars.virginia.gov.

Please scan this code to let us know
what you think about the Roadmap!





Virginia Alzheimer's Disease and Related Disorders Commission

Virginia Department for Aging and Rehabilitative Services

Virginia Department of Health

Dementia-Capable Virginia

An initiative of the Virginia Alzheimer's Disease and Related Disorders Commission and the Department for Aging and Rehabilitative Services