A ROADMAP FOR DEMENTIA

Getting diagnosed with dementia can feel scary, sad, and cause worry.

This roadmap is for people with dementia and their care partners, such as family or friends, to help prepare for the future.

This roadmap does not need to be read all at once – sections can be read in any order at any point that is most helpful.

R2P2

Colorado Program for Patient Centered Decisions

Anschutz
School of Medicine

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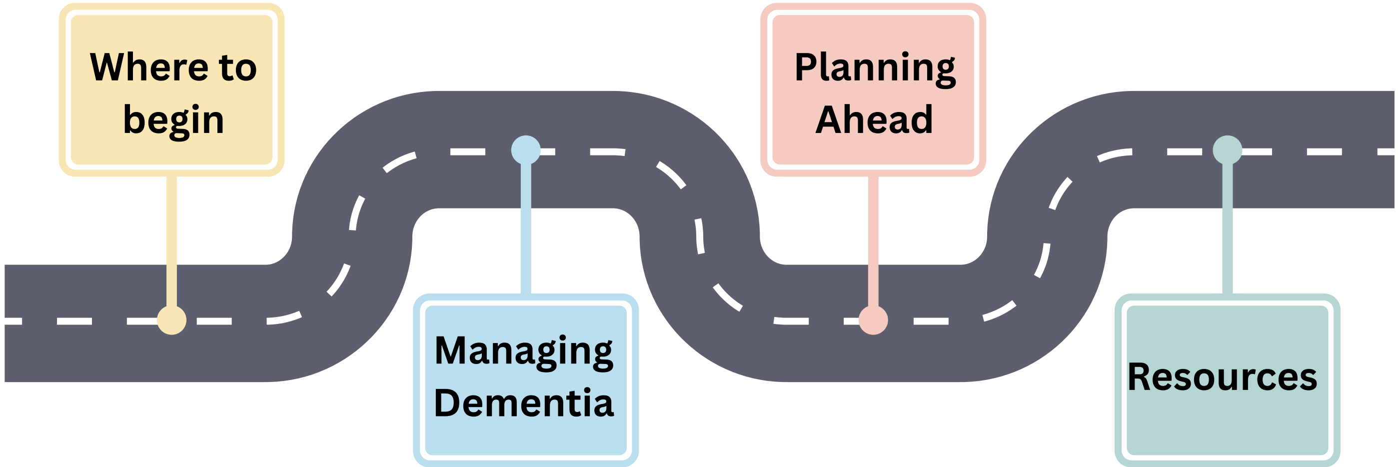

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Where to Begin

This section will cover:

- Learning about dementia
- Sharing a diagnosis
- Health professional support

Words highlighted in **ORANGE** are defined in the glossary.

Learning About Dementia

What is dementia?

Dementia happens when brain cells get damaged or die. This makes it hard for the brain to work properly. The brain has different areas that control things like memory, judgment, language, attention, and movement, among other things. This is called **cognition**. When cells in one of these areas are damaged, that part of the brain may stop working as it should.

What does it mean to have dementia?

Dementia is a neurological problem, meaning it affects how the brain works. People with dementia have changes in cognition which can impact many areas of the brain, such as memory, but also mood and behavior. Some things that may become harder for people with dementia include:

- Recalling memories, especially recent memories
- Communicating with and understanding others
- Making decisions
- Solving problems
- Understanding visual information in the same way as before
- Doing familiar tasks like putting on clothes in the correct order

How is dementia diagnosed?

Dementia is diagnosed by a doctor. Primary care **clinicians** or **neurologists** will run different cognitive tests to rule out other medical causes before giving a diagnosis. Often people with dementia have memory problems that interfere with their every day tasks. Dementia impacts a person’s ability to do things day-to-day.

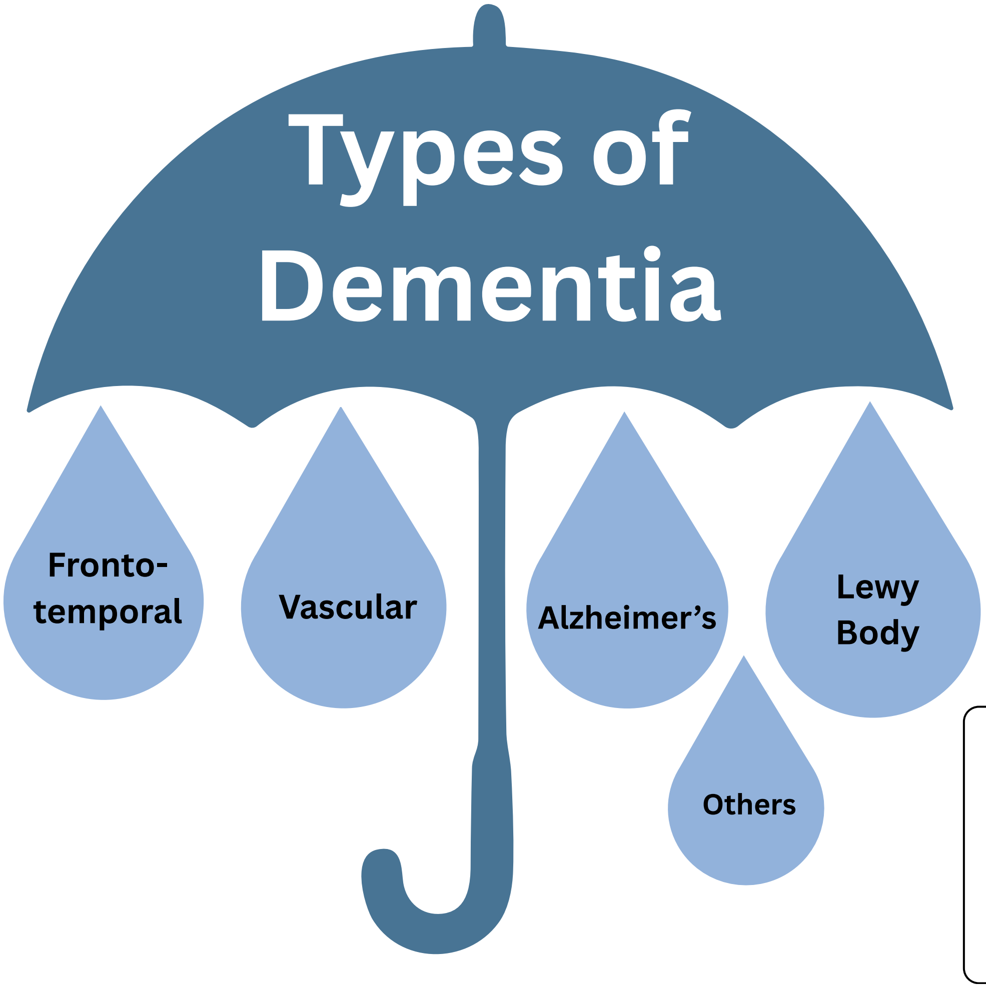
Who gets dementia?

Millions of people have dementia. However, we do not know why some people get dementia and others do not. While dementia is more common as we age, it is not a normal change in brain health. Dementia diagnosed before age 65 is known as early onset dementia. Like many diseases, dementia can affect anyone, but it is important to remember it is never anyone’s fault they get dementia.

Learning About Dementia

Is Alzheimer's the only type of dementia?

No, there are many types of dementia, and each can cause different symptoms. Alzheimer’s is the most common type, but other common types include Vascular, Lewy Body, and Frontotemporal dementia. People often need to see a few doctors to figure out what type of dementia they have.



The Resources section has more information on the different types of dementia

Will dementia get worse?

Sadly, there is no cure for dementia and symptoms will continue to get worse over time for most types of dementia. Dementia can make the symptoms of other health conditions, like heart disease or diabetes, worse. Other health conditions can also make dementia symptoms worse. It is hard to know how quickly things will change because different types of dementia progress at different rates, and each person has unique symptoms. While people with dementia may notice some changes, they might not be fully aware of problems. It is important for people with dementia to talk to their doctors about all their health conditions to get the care that is right for them.

Learning About Dementia

Healthy Brain Aging means as people age, the changes in their brains should be small and not affect daily life much. It is normal for some things like planning, organizing, or thinking of a word, to take a little longer. For example, misplacing keys does not mean someone has dementia.

Mild Cognitive Impairment (MCI) is a change in brain health. People can still do many daily tasks on their own, but it may take longer or feel harder. They might get dementia in the future, but it depends on what causes the mild cognitive impairment.

Dementia causes big changes in how people's brains function. This makes doing daily tasks harder. Dementia is often broken into early, middle, and late stages. Early-stage signs include taking more time to finish tasks, forgetting names and places, or having less energy to be social. Later-stage signs might include not being able to do daily tasks alone, like dressing and bathing, and needing help to stay safe.

Sharing A Diagnosis

Some people with dementia may decide to tell family, friends, or other people about their diagnosis. There is no right or wrong way to have this conversation with others. It is up to the person with dementia to decide if, when, and how they might share this news.

Keep in mind some people with dementia may:
- Not want to share this news with everyone.
- Need time to process the news themselves.
- Want to share the news in different ways with different people.

People who decide to share the news may find it helpful to:
- Give the person a heads up that they have something important to talk about.
- Adjust how they share the news with the person they are telling. They know their friends and family best, so for example, calling someone on the phone may be better than sending an email.
- Ask someone they trust to help share the news with others.
- Consider telling people over time rather than all at once.

People with dementia and care partners may find it helpful to:
- Know people may react differently to learning that a loved one has dementia. They may be afraid, angry, surprised, or they may deny it. They may withdraw or they may ask a lot of questions.
- Give the person time to process the news.

Health Professional Support

There are many health professionals skilled in supporting people with dementia and their care partners. **Some types of health professionals include:**

Medical workers who help manage regular care and refer people with dementia to other experts include:

- Primary care clinicians: doctors focused on overall health of their patients
- Geriatricians: doctors focused on care for older adults
- Advanced health practitioners: nurse practitioners or physicians assistants

Other medical specialists who help with specific needs include:

- Neurologists: doctors who specialize in brain health.
- Palliative care clinicians: provide comfort focused care.
- Pharmacists: help with **medications** and supplements

Other specialists include:

- Social workers, care managers/navigators, community health workers: help coordinate care, find and access resources.
- Psychologists/Behavioral Mental Health Workers: support mental health and wellbeing
- Occupational/Physical Therapists: help with movement and daily activities
- Speech Language Therapists: help with communication

People with dementia and their care partners may want to ask their doctors some of these questions:

- What type of dementia do I have?
- What stage am I in?
- Can I keep doing my usual activities?
- Are there treatments that can help?
- What resources or programs are there to support me and my family/loved ones?
- How do I take care of other health needs besides dementia?
- What else can I be doing to keep myself healthy?

Tip Many people find it helpful to write down other questions they have before seeing a health professional, and to take notes during the visit.

Managing Dementia

This section will cover:
- Managing symptoms
- Managing legal matters
- Paying for care
- What matters most?

Words highlighted in **ORANGE** are defined in the glossary.

Managing Symptoms

While there is no cure for dementia, there are things people with dementia can do to help with symptoms. Some people may not be able to do all these things. That is okay. What matters most is caring for themselves in a way that is right for them. These strategies are behaviors that are good for all phases of life that may be particularly helpful for dementia:

Get good sleep.

- Go to bed and wake up at the same time each day.
- Keep naps under an hour and avoid napping late in the day.

Be active.

- Go for a walk, bike ride, clean house, garden, or do any enjoyable physical activity to build up heart rate and strength.
- Aim for at least 20 minutes, five days a week.

Practice healthy eating habits

- Eat foods rich in fruit, vegetables, and whole grains.
- Avoid drinking alcohol and smoking.

Manage stress.

- Try deep breathing or things to relax.
- Focus on changes in feelings and tell others about sad or anxious feelings, or low energy to do things.

Keep the brain active.

- Read or do puzzles. Listen to music.
- Work on crafts or other artistic projects.

Connect with others.

- Go to a park or museum with friends.
- Spend time with family.
- Join a support group or volunteer.

For potential medications to discuss with a doctor, go to the Resources section.

Tip Remember to pay attention to other health conditions like high blood pressure. Use hearing aids or glasses if needed to manage hearing and vision loss.

Managing Legal Matters

Advance directives are legal documents that help people plan for medical and financial choices in their future. Setting up advance directives lets others know what people want for their care if they become unable to make decisions on their own. Complete the forms as soon as possible.

Tips for setting up advance directives:

- Choose a trusted person who is over 18 and easy to reach. These forms should be filled out with this person, so they know their loved one's wishes.
- Share copies of these forms with doctors, clinics, any hospitals visited, and banks if needed.
- It may be helpful to get support from a social worker, doctor, eldercare lawyer, or legal support organization.
- Some people may also complete a **Living Will** or **Five Wishes document** to help others know what they want for their care.

Tip It is important to fill out these forms while loved ones can still make decisions for themselves. Otherwise, the chosen decision maker may have to take extra steps such as getting **guardianship** for healthcare decisions or **conservatorship** for financial decisions to make decisions for their loved one.

On the next page is a checklist with details on **advance directives**.
You can use it to check off the forms as you complete them.

Managing Legal Matters

Check off these boxes as soon as the forms are complete:

☐ **Medical Durable Power of Attorney**

- What it does: Lets someone talk to health professionals and make choices about a person's health care if they are not able to. A health care proxy allows someone a person with dementia chooses to talk about their healthcare only.
- Why it is needed: People with dementia will not always be able to make healthcare decisions for themselves.
- What to do: Complete and sign a Medical Power of Attorney Document and have it signed by two witnesses.

☐ **Medical Orders for Life Sustaining Treatment (MOST)**

- What it does: This is a common form that anyone over 18 is encouraged to complete. It lets health professionals and emergency responders know what treatment is wanted, such as getting chest compressions or going to the hospital if someone's heart stops working.
- Why it is needed: People with dementia will not always be able to tell others what treatment they want.
- What to do: Complete and sign a Medical Order for Life Sustaining Treatment form with their doctor.

☐ **Financial Power of Attorney**

- What it does: Lets someone make choices about a person's finances if they are not able to.
- Why it is needed: People with dementia will not always be able to make decisions about their money and other finances on their own.
- What to do: Complete and sign a Financial Power of Attorney form. This must be notarized and may require a special note saying the person signing it can still make decisions on their own at the time of signing.

☐ **Health Insurance Portability and Accountability Act (HIPAA) Release**

- What it does: Allows a person with dementia's doctor to share protected health information with someone they choose.
- Why it is needed: A person with dementia will not always be able to grant the release of their protected health information.
- What to do: Complete and sign a state-specific HIPAA form.

Paying for Care

Listed below are different ways that may help pay for care other than private health insurance. It is often recommended to get help from a social worker, case worker, or benefits navigator to see what care may be covered.

Medicare

- For people 65 and older
- For people younger than 65 with Social Security Disability Insurance
- In some regions, additional support may be offered through Guiding an Improved Dementia Experience (GUIDE) programs.

Medicaid

- For people with lower income or limited resources
- In some regions, additional support may be offered through Program of All Inclusive Care for the Elderly (PACE)

Veterans Benefits

- Available for people with qualifying military service
- Contact 1-800-827-1000 to check home health care, care partner **respite**, adult day programs, and other veteran benefits.

Type of Care	Medicare	Medicaid
Doctors visits and hospital care	Yes	Yes
Nursing home care	Covers up to 100 days after a hospital stay	Covers long-term care
Personal Care care partner who helps with daily activities (bathing, dressing)	No	Yes
In-home health aide	May cover with certain medical needs	Covered under Personal Care Services
Memory Care	No	May Cover
Assisted living	No	May Cover
Adult day support	No	Yes

What Matters Most?

Many people with dementia find it helpful to think about what matters most to them as they adapt to life with dementia. This page can be worked through alone, or with a trusted person at whatever pace feels best. These answers may change, and that is okay. This worksheet can also be helpful to bring to appointments with doctors.

Use the spaces below to respond to the questions:

What are my hopes and worries?

What brings me joy?

What does my independence mean to me? How important is it?

How will I stay connected to what I find meaningful?

What does dignity look like for me?

What Matters Most?

How do I want my loved ones to support me?

What do I want my life to look like?

How am I adapting to life with dementia?

How am I preparing for the future?

What do I want to know more about?

Tip Some people like to make "legacy" documents (photos, stories, letters) to leave to their loved ones. There are even resources online to support this.

Planning Ahead

This section will cover:

- Planning for changes
- Planning for late stages
- Safety considerations
- Communication
- Care Partner support

Words highlighted in **ORANGE** are defined in the glossary.

Planning for Changes

Dementia causes changes that can happen slowly or quickly and may not be obvious right away. People with dementia are still themselves but they may not notice changes taking place.

Changes in mood and behavior can include:

- Feeling tired more often or more easily.
- Feeling sad, worried, upset, or angry more often or more easily.
- Not wanting to do things that were fun before.
- Feeling like people are taking or hiding things.
- Feeling confused, especially in the late afternoon or evening (called **sundowning**).
- **Shadowing** or following people around.
- Needing help with personal care such as showering or dressing.

Changes depend on:

- The type of dementia a person has
- The stage of dementia they are in

People with dementia and care partners may feel very sad, anxious, frustrated, lonely or overwhelmed by these changes. **The following strategies might help both people with dementia and their care partners:**

- Talking to a mental health worker about their feelings.
- Talking to their doctor when needed.
- Spending time with people who support them or reaching out to family and friends who can help with things like cooking and running errands.
- Joining a support group to meet others who get what they are facing.
- Checking health insurance for home health aide coverage.
- Exploring programs available in the community such as:
  - Adult activity centers: places where people with dementia can do activities and connect with others.
  - Memory cafes: spaces for people with dementia and care partners to meet up and connect with others going through similar things.

Planning for Later Stages

It is important to know that changes can become more intense as people with dementia enter later stages of the disease. Symptoms will look different for everyone, but loved ones with dementia may struggle with personal care needs, such as going to the bathroom or eating or their own.

These are hard changes to think about, and even harder to plan for, but it is important to talk about these possible changes as early as possible so people with dementia can make their end-of-life wishes known. Others have found it helpful to explore further information and resources to begin thinking about how to prepare before a loved one enters later stages.

Many people with dementia and their care partners want to live at home as long as possible. Yet for some people with dementia, living at home may not always be an option. Others have found it helpful to check in often and ask themselves:

- Is it time for more help?
- What would need to happen to consider a living change?

Living changes could include:

- Independent living: for people who still do most things on their own but want a safe place to live and connect with others.
- Assisted living: for people who need help with daily activities like getting dressed or taking medicine.
- Skilled nursing facility: for people who need an ongoing high level of care.
- Memory care: for people with dementia who need full-time support.
- Palliative care: supports people with dementia and care partners throughout their illness, but it can also be helpful during later stages. This type of care focuses on relieving symptoms, pain, and stress and can also provide emotional and spiritual support.
- Hospice care: for people nearing the end of their lives. It includes medical, emotional, and spiritual support focused on comfort. Many people with dementia and their care partners consider hospice near the end of life.

Safety Considerations

Conversations about safety can be hard and full of emotions. There are things people with dementia and their care partners can do to keep each other safe. Talking to health professionals can be a great step to take if struggling to have these conversations.

People with dementia and care partners find it helpful to ask themselves the question: “What will make us feel safe?” when going through this section.

Home Safety Tips

- Keep walking areas like hallways clear by moving furniture and objects out of the way to avoid tripping.
- Mark walking areas with light strips to see walkways clearly.
- Install handrails to help with balance.
- Consider moving the living space to the ground floor to avoid stairs.
- Replace rugs that slip with traction, especially in bathrooms.
- Consider other ways to keep spaces open for things like wheelchairs.
- Make sure carbon monoxide and smoke alarms are working properly.
- Put bells or video cameras on doors that lead outside to limit **wandering**.
- Disable kitchen appliances such as the stove and think about where to safely store utensils like knives, such as in locked cabinets.
- Securely store dangerous appliances or materials.

Medications

- Set alarms or use a lockable pill holder or an automatic pill dispenser to take the right amount of medication at the right time each day.
- Keep a list of how often and how much of each medication is taken, as well as any other things used such as health devices, over the counter medications and supplements.

Tip Bring a medication list when visiting the doctor to keep records up to date.

Safety Considerations

Driving

Many people find meaning in driving because it gets them places, gives them a sense of independence, and allows them to stay connected with others. However, people with dementia should prepare to stop driving at some point, before it becomes dangerous to themselves, loved ones, or others on the road.

Some people with mild symptoms might be able to continue driving by:

- Driving shorter distances only during the day
- Driving during less busy times
- Driving on familiar roads and avoiding highways or interstates

Signs that suggest a loved one with dementia might need to stop driving:

- There are new dents on the car, but they do not know how they got there.
- They get lost while driving.
- They confuse the brake and gas pedal.
- They misread or do not know the meaning of road signs.
- There are changes in their driving skills.

Care partners can help people with dementia stop driving by:

- Talking about stopping driving with trusted family, friends, or health professionals.
- Talking about it over time rather than all at once.
- Asking friends or family to drive people with dementia to the store or other places they enjoy.
- Checking eligibility for access to ride share programs through the local Area Agency on Aging or a local Aging and Disability Resource Center.

Tip Some people might be able to get their driving skills tested by an occupational therapist and have this covered through insurance, but it can be expensive to take a private driving test.

Safety Considerations

Firearms

Many people with dementia and their care partners decide to remove firearms from their home to limit serious accidents. If keeping firearms in the home, use these strategies:

- Keep both ammunition and firearms in a secure place, like a locked safe.
- Always store ammunition separately.
- Make an inventory of all firearms so care partners know where they are.

Wandering

People with dementia may wander to unfamiliar places, or places they know, without knowing how or why they got there. These strategies can help:

- Put lights around the home that stay on all night.
- Put bells or alarms on doors to signal when someone goes outside.
- Label doors with signs or pictures to show what each room is for.
- Notice if certain times of day or events trigger wandering.
- Reach out to local police or service groups so they know who to call if someone with dementia wanders.
- Get a wearable health device such as a medical life alert bracelet that contains important information about the person with dementia.
- Turn on cell phone tracking features or use other GPS tracking devices developed with dementia in mind.
- Ask neighbors or friends to reach out if they notice someone with dementia is alone or dressed oddly.
- Make a list of places someone with dementia might go such as where they used to live, work or enjoyed going.
- In some states, people with dementia can get a special identification card that lets emergency health workers know they may need extra help.

Safety Considerations

⚠ Unsafe Behavior

People with dementia may sometimes act in a way which feels dangerous to those around them. If this happens, care partners should:

- Try to stay calm by talking gently and redirecting their attention elsewhere.
- Leave the room if it feels unsafe.
- Call others for help, such as other family, friends, or 911 if needed.

Care partners should consider making a contact list with phone numbers in a place they can quickly find if needed.

Tip Contact the free Alzheimer's Association help line at 800-272-3900 for more information on strategies to stay safe.

Communication Tips

Many people are uncertain about how to talk to a loved one with dementia. They may get easily frustrated or overwhelmed. Here are some helpful reminders for care partners. These tips can be shared with family and friends too.

Accept what a loved one with dementia is facing. People with dementia are still themselves, but they cannot control the symptoms of dementia getting worse and may seem less like themselves over time.
- Think about meeting a loved one with dementia where they are rather than blaming them for the symptoms they are struggling with.

Focus on connection over correction. A loved one with dementia cannot control changes in their brain, so do not argue or point out problems.
- Find things that can be done together and use praise when it helps.

Show empathy and be kind.
- Do not talk as if a loved one with dementia is not present - include them in conversation.

Be patient by giving them extra time to reply or react.
- Suggest words if they have a hard time finding an answer.
- Try to ask questions in different ways if they do not understand what is asked.

Use clear language and speak slowly and calmly.
- Explain things in short sentences with simple words.
- Make sure a loved one with dementia is focused on who is speaking before starting to talk.
- Use full names instead of stand-in words like he, she, or they.
- Use yes or no options rather than open-ended questions.

Communication Tips

Use body language to reassure and remind a loved one with dementia they are safe, and they are not alone.

- A loved one with dementia may feel confused, scared, or lonely. These feelings are real to them even if they do not make sense to others.
- Sit with them and hold their hand, pat their knee, or gently rub their back. If they are sitting down, meet their gaze by moving to their eye level.

Keep it light.

- When mistakes happen, like putting the ice cream in the fridge instead of the freezer, sometimes it’s best to not take things too seriously.

Pay attention to triggers by noticing what makes a loved one with dementia upset.

- Look for signs they might be having a hard time, such as leaning away, slouching, or anxiously fidgeting.
- They may be thirsty, hungry, or need to go to the bathroom but may be unable to explain their needs.
- Respond to the triggers by redirecting the topic or changing the setting. If they seem overwhelmed, turn down loud noises or reduce the number of people around them.

Focus on what a loved one with dementia can still do and find tasks they can succeed at to help them feel good.

- Do not ask questions that rely on short-term recall, like, “Do you not remember what I just told you?” Instead, ask about a fun trip they took years ago.
- Break tasks into small steps.
- Focus on talking about things that bring joy instead of stress.

Communication Tips

Focus on your reactions as a care partner, family, or friend. Pause and take deep breaths before answering if upset.

- Try not to be offended if their actions seem wrong. They might not mean to be upset.
- Be prepared to change your plan and try a different approach if struggling to communicate.
- Recognize what might be triggering for you as a care partner, friend, or family member. Use mottos like “They are having a rough day; this is not anyone’s fault; they are trying their best” to counter frustration that comes up.
- Accept upset feelings and remember communication will not be perfect all the time.

To prepare others for talking to a loved one with dementia:

- It may be helpful to keep a journal or list of things that upset a loved one and share this with others, so they know what is triggering.
- Share how a loved one likes to be addressed.
- Share how a loved one likes to be talked to (what their communication language is). For example, if a loved one with dementia is trying to say, “I feel off today” and a family member says overly positively, “oh yeah you sure do” then they could be frustrated by that response.

Tip It is okay if it is hard to communicate sometimes! Remember that people with dementia and care partners are doing the best they can to adapt to many changes.

Care Partner Support

Many people who care for a loved one with dementia have a hard time accepting changes in their relationship. They may have a sense of losing someone even though their loved one is still alive. This confusing type of grief is called **ambiguous loss**. These feelings can be hard to explain to others who may not understand what a care partner is facing, or what to say or how to help. Family and friends may cope by denying changes or withdrawing. This may feel lonely, but **care partners are not alone.**

Here are strategies shared by others who have cared for a loved one with dementia:

Learn how to ask for help.

- Take a break by exploring options for respite care. This is service where someone else helps care for a loved one with dementia for a little while. Find more about respite care in the Resources section.
- Be direct about what your needs are.
- Be clear about what is needed. For example, say “I need someone to drive Dad to the doctor on Friday.”

Talk to other care partners who get it.

- Join a support group online or in person, to talk to others who understand what this feels like.

Be patient while figuring out what works best.

- Be open to other creative ideas that might be helpful, like journaling.
- Laughter offers a source of strength, so use it as often as possible.

Remember the best thing to help a loved one with dementia is to take care of yourself as a care partner.

- Make a list of things you enjoy.
- Take the time to schedule these activities to make sure they happen.

Care Partner Support

Remind yourself you are doing your best. Care partners rarely hear how much they are appreciated for providing care for a loved one with dementia.

- Many care partners feel they are not doing enough or feel bad about how they care for a loved one with dementia. This sense of guilt is normal, but it is important to remember that caring for a person with dementia is hard.
- You will get tired, you will need help, and there will be tough days. This is perfectly okay- it does not mean you are a bad care partner. It means you are human.

Keep checking in with yourself. Ask yourself the following questions throughout your journey in caring for a loved one with dementia:

What does help look like to me?

What do I want to know more about?

What do I want for my loved one with dementia?

What is going well in my loved one’s care?

Care Partner Support

What kind of help do I need right now?

What kind of help will I need in the future?

What do I want my life to look like?

What are my hopes and worries?

What steps am I taking to find support and care for myself?

What makes me happy? Am I doing those things?

Resources

This section will cover:
- Resources
- Glossary
- Medication Information
- Types of Dementia

Resources

Alzheimer’s Association
Leading organization for information and resources on Alzheimer’s disease.
Tel : 800-272-3900
https://www.alz.org/

Dementia Friendly America
Provides resources on community support for people with dementia and their care partners.
Tel: 202-872-0888
https://dfamerica.org/

Seniors Blue Book
Provides resources for aging.
Tel: 800-201-9989
https://seniorsbluebook.com/

Eldercare locator
Referral source to find care for older adults.
Tel: 1-800-677-1116
https://www.usaging.org/eldercareloc

Guiding An Improved Dementia Experience (GUIDE) Model
Provides information on GUIDE programs and eligibility requirements.
Email : GUIDEModelTeam@cms.hhs.gov
https://www.cms.gov/priorities/innovation/innovation-models/guide

Safety In Dementia
https://safetyindementia.org/
Provides information on making decisions about safety and dementia.

Feeding Options Decision Aid
Tips for making decisions about feeding options for a loved one in later stages.
https://decisionaid.ohri.ca/docs/das/Feeding_Options.pdf

Glossary

Advance directive: A legal form that tells doctors and care partners what medical care a person wants if they cannot speak for themselves.

Ambiguous loss: The feeling of losing someone, even though they are still physically present.

Care partner: A person who helps take care of someone (includes family and friends).

Clinician: A health professional who helps patients by checking symptoms, giving advice, and providing care.

Cognition: The brain’s ability to think, learn, remember, and make decisions.

Conservatorship: When a court chooses a person, called a conservator, to make decisions for someone who cannot take care of themselves. The conservator may help with money, health care, or daily needs.

Financial power of attorney: A legal document that lets someone you trust manage your money and bills if you cannot.

Five Wishes document: A guide that lets people write down their health care wishes.

Guardianship: When a court chooses someone, called a guardian, to take care of a person who cannot make decisions on their own. The guardian may help with things like health care, safety, and daily needs.

Living Will: A legal paper that says what kind of medical care a person wants at the end of their life.

Medication: Drugs or medicine that help treat sickness or symptoms.

Medical Durable Power Of Attorney: A legal paper that names someone to make medical decisions for you if you cannot.

Medical order for life sustaining treatment: A medical form that tells doctors what treatments to give or not give to keep a person alive.

Neurologist: A doctor who spealizes in brian health.

Respite: A short break for a care partner to rest while someone else takes care of their loved one.

Shadowing: When a person with dementia follows someone closely because they feel confused or scared.

Sundowning: When people with dementia get more confused or upset in the late afternoon or evening.

Wandering: When a person with dementia walks away from a safe place without knowing where they are going.

Medication Information

Here is a list of medications that may help with symptoms. While these medications will not cure dementia, they may help people with dementia stay in early stages for longer. Some medications are better for certain types of dementia. Some medications may be harmful for some types of dementia. **Always check with a doctor about the potential benefits and side effects and to explore if any of these medications could help you.**

Cholinesterase inhibitors: donepezil (Aricept), rivastigmine (Exelon), and galantamine (Razadyne)

- What they do: May helps with memory, thinking and daily tasks. It may also help reduce seeing things that are not there in Lewy Body dementia.
- When used: Started in early and middle stages and through later stages if it is not causing problems.
- Possible side effects: Upset stomach, lightheadedness, slower heart rate, and trouble sleeping.

N-methyl-D-aspartate (NMDA) receptor antagonist: memantine (Namenda)

- What it does: Helps with memory, thinking and daily tasks.
- When used: Middle through later stages if it is not causing problems.
- Possible side effects: Bad mood.

Antidepressants

- What they do: Helps with bad mood, worry, and fear.
- When used: At any point based on symptoms.
- Possible side effects: Initially can worsen mood problems. Dizziness, upset stomach, and changes in sleep.

Antipsychotics

- What they do: Helps with seeing things that are not there, unreal beliefs, or mood and behavior problems.
- When used: If other medications are not helping.
- Side effects: May cause shaking or slower movements. Can cause heart problems.

Sleep medicines

- Trazodone: Can help with bad mood.
- Mirtazapine: Can help with bad mood and poor appetite.
- Suvorexant: The only FDA-approved medication to help with sleep issues specifically in Alzheimer’s disease.

Anti-amyloid medication (lecanemab or donanemab)

- What they do: New medication only for dementia caused by Alzheimer's disease that removes amyloid and slows down the rate of decline.
- When used: Only for Alzheimer’s disease in earlier stages. These medications have not been shown to help in more advanced cases.
- Possible side effects: Can cause swelling and bleeding in the brain, which requires regular MRIs. Infusions can trigger reactions.

Types of Dementia

Alzheimer's Disease

Key Points:

- Most common type of progressive dementia.
- Specific proteins found in the brain, called amyloid and tau, are associated with damage to brain cells.
- This can lead to changes in:
  - Memory
  - Planning tasks that need many steps or being able to move between tasks when interrupted
  - Attention
  - Understanding spoken or written communication
  - Understanding visual information
  - Problem solving
  - Performing learned motor tasks
- Alzheimer’s disease is different for everyone. A person’s specific symptoms depend on what part of the brain is affected.

Vascular Dementia

Key points**:**

- Vascular dementia happens when there is damage to the brain caused by problems with blood flow. Strokes or narrowed blood vessels might cause this.
- Symptoms can vary depending on which part of the brain is damaged.
- The main goal of caring for vascular dementia is to stop further damage. Your health care team may focus on treating other health problems like high blood pressure, high cholesterol, and diabetes. They might urge you to limit the use of tobacco which can make damage to the brain and symptoms worse.
- There are no FDA-approved medications for vascular dementia, but certain medications may help with symptoms. Always talk to your doctor to learn about what is the best plan for care for you.

Types of Dementia

Frontotemporal Lobar Dementia

Key points:

- Many other proteins are seen in Frontotemporal lobar dementia.
- Like other types of dementia, symptoms vary based on the part of the brain.

Here are some types of Frontotemporal Lobar dementia based on the symptoms:

- Behavioral variant frontotemporal dementia: Changes in brain function and actions such as:
  - Making choices quickly without thinking of consequences.
  - Not being able to interpret other people's feelings as well.
  - Having less interest in doing things.
  - Doing the same thing over-and-over.
  - Changes in diet including eating things that are not food.
- Motor neuron disease-frontotemporal spectrum disorder or ALS (amyotrophic lateral sclerosis also called Lou Gehrig's disease), which has changes in brain function and action as well as:
  - Worsening muscle weakness
  - Twitching
- Semantic variant primary progressive aphasia: Having a hard time knowing what things are or knowing the meaning of ideas.
  - Non-fluent primary progressive aphasia: Affects brain cells that are important for the motor movements to produce speech, leading to slow, and labored talking.
  - Progressive supranuclear palsy: Can affect brain cells important for balance and coordination, eye movements, speech, and thinking.
- Limbic-predominant age-related TDP-43 encephalopathy (LATE). LATE can look like amnestic Alzheimer's disease, but does not have problems with amyloid or tau, rather it is seen with a protein called TDP-43. It is often seen in people over 75 years old with:
  - Short-term memory loss.
  - Trouble being able to recall facts or the meaning of words.
  - Corticobasal degeneration: Can affect brain cells important for limb movement, speech, and thinking. Problems often include slowness or clumsiness in movement or speech.
- There are no medications to slow frontotemporal lobar dementia, but some medications can help manage symptoms such as changes in mood.
- Some medications used to help symptoms in other types of dementia may make symptoms worse for people with frontotemporal lobar dementia. Always talk to your doctor to see what is best for you.

Types of Dementia

Lewy Body Dementia

Key points**:**

- Lewy body dementia includes both dementia with Lewy Bodies (or synuclein, a type of protein) and Parkinson’s Disease Dementia. The main difference between dementia with Lewy Bodies and Parkinson’s disease dementia is based on which symptoms show up first. Changes in thinking are commonly worst first for dementia with Lewy Bodies and changes in movement is worst first for Parkinson’s disease dementia.
- Health professionals may have difficulty figuring out that a person has dementia with Lewy Bodies. Some people may need to talk to many doctors before getting a diagnosis.
- Symptoms can include:
  - Seeing things that are not there, like animals, people, or small creatures.
  - Moving slower and feeling unsteady with near or actual falls.
  - A new tremor or shaking body parts like arms, hands, legs, feet, or head.
  - Acting out dreams while sleeping, which can hurt you or the person sleeping next to you.
  - Big changes in how aware or awake you are from one moment to the next.
  - Reduced or loss of smell.
  - Having a hard time passing bowel movements or urinating.
  - Feeling lightheaded and/or dizzy, especially after changing positions after lying or sitting down for a long period of time.
  - Changes in vision may make it hard to focus on things, including following the lines while reading.
  - Difficulty swallowing regularly, which can lead to drooling.
- There are no medications that slow down Lewy body, but some medications can help with symptoms. Always talk to your doctor to learn about what is the best plan for care for you.

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