

I THINK MY LOVED ONE  
*Has Dementia.*

A Caregiver's Guide

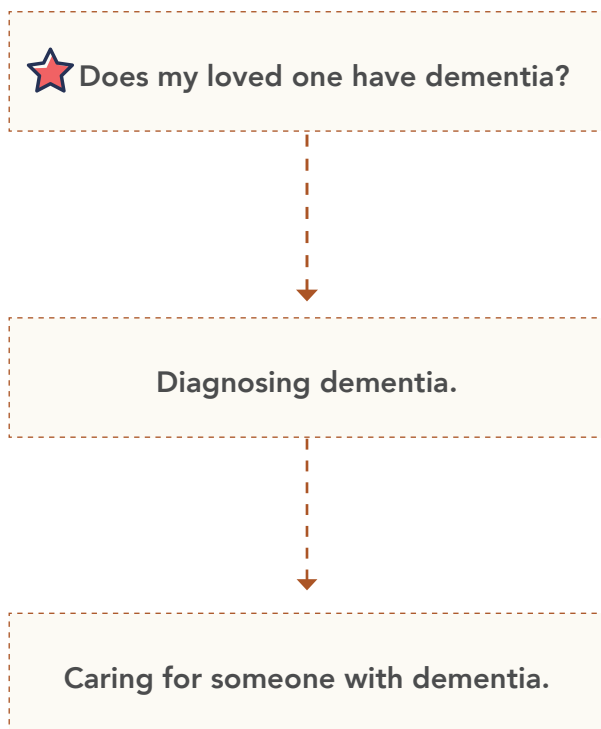
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**Capital Caring**

PALLIATIVE CARE | COUNSELING | HOSPICE

# The Caregiver's Journey



**You are here.** Your gut is telling you something has changed with a person you love. They're forgetting that walk you took together just yesterday, and they're a bit more moody than usual.

The Capital Caring team knows this stage very well, both from our clients and our personal experiences. So we understand – it's scary. But know this – you're taking the perfect step. Listening to your gut when you know something's changed is the first and most important part of mapping out a plan that meets the needs of you and your loved one, rather than allowing the illness to dictate your path forward. We want to empower you through the process. We'll help you understand what's happening, and how to plan and advocate for your loved one's new needs and your own. At this stage, it may seem like everything else is about your loved one, but this guide is about, and for, you.

# PART I: DOES MY LOVED ONE HAVE DEMENTIA?

*Let's start here. What is dementia?*

Dementia is not one specific disease. Instead, it's a general term used to describe a group of symptoms associated with a decline in memory or thinking so severe that it impacts a person's ability to perform everyday activities. These symptoms occur because nerve cells (neurons) in parts of the brain involved in cognitive function have been damaged or destroyed.

## **IS IT DEMENTIA OR ALZHEIMER'S?**

Good question. Alzheimer's and dementia are intertwined and often used interchangeably. Remember, dementia is a group of symptoms, but Alzheimer's is a progressive brain disease, one in which brain changes may begin 20 years or more before symptoms like dementia even occur. Alzheimer's is the most common cause of dementia, accounting for 60-80% of cases. That is why you often hear doctors use the term "Alzheimer's dementia" – the disease is resulting in dementia symptoms.

## **HOW CAN I TELL IF MY LOVED ONE HAS DEMENTIA?**

According to the Alzheimer's Association, if at least two of the following mental functions are significantly impaired, the issue can be considered dementia:

- Memory
- Communication and language
- Ability to focus and pay attention
- Reasoning and judgment
- Visual perception



## **COULDN'T IT JUST BE SIGNS OF AGING?**

Another good question. Some of the symptoms mentioned above could in fact just be signs of other health or age-related issues, such as head trauma, problems with vision and hearing, hormone disruptions or infections to name a few. The Alzheimer's Association offers a helpful guide on understanding the ten warning signs of dementia and how they differ from normal signs of aging.

# The Signs of Dementia

SIGNS OF DEMENTIA	NORMAL SIGNS OF AGING
<p><b>Memory loss that disrupts daily life</b> <i>Example: Forgetting information that was just obtained, forgetting dates and events and asking the same thing many times.</i></p>	<p>Sometimes forgetting names or appointments, but recalling them later.</p>
<p><b>Trouble planning or solving problems</b> <i>Example: Forgetting how to follow a familiar recipe or working with numbers in their budget.</i></p>	<p>Occasionally making small errors when balancing a checkbook.</p>
<p><b>Trouble completing familiar tasks</b> <i>Example: Trouble driving to a place they've gone many times before or remembering the rules to a familiar game.</i></p>	<p>Sometimes needing help using settings on a microwave or television.</p>
<p><b>Confusion about time or place</b> <i>Example: Losing track of dates or seasons and forgetting where they are and how they got there.</i></p>	<p>Forgetting the day of the week but remembering later.</p>
<p><b>Trouble understanding images and spatial relationships</b> <i>Example: Trouble reading, judging distance, or determining color.</i></p>	<p>Vision changes caused by cataracts or glaucoma.</p>
<p><b>Trouble with words in speech or writing</b> <i>Example: Stopping mid-conversation and having no idea how to continue, repeating the same thing many times, trouble finding the right word or calling familiar objects by the wrong name.</i></p>	<p>Sometimes searching for the right word in conversation, but once someone else says it, knowing that was the word they were looking for.</p>



SIGNS OF DEMENTIA	NORMAL SIGNS OF AGING
<p><b>Losing things and being unable to retrace steps to find them</b></p> <p><i>Example: Putting often-used things in unusual places, inability to recall what they did earlier in order to find lost things, accusing others of stealing lost things.</i></p>	<p>Sometimes losing things but retracing steps to find them.</p>
<p><b>Showing poor judgement</b></p> <p><i>Example: Paying large sums of money to telemarketer or goods they never splurged on previously and paying less attention to keeping themselves clean.</i></p>	<p>Making a bad decision once in a while.</p>
<p><b>Withdrawal from work or social activities</b></p> <p><i>Example: Beginning to remove themselves from hobbies, social activities or work projects; Trouble keeping up with favorite sports teams or how to participate in a hobby they've always loved.</i></p>	<p>Sometimes feeling like they don't have the energy for work or social obligations.</p>
<p><b>Changes in mood and personality</b></p> <p><i>Example: Getting easily upset at places where they are outside of their comfort zone; Becoming confused, suspicious, depressed, fearful or anxious.</i></p>	<p>Becoming irritable when a long-held routine is disrupted.</p>

<sup>3</sup> <https://www.alz.org/10-signs-symptoms-alzheimers-dementia.asp>

## PART II: DIAGNOSING DEMENTIA

### *I see these signs, what do I do?*

First, take a breath, a walk, or whatever activity helps you clear your head. Coming to terms with seeing these changes in someone you love can be hard. Again, we want to help you remember you're doing exactly what's right – early detection is the key to controlling your path forward and that of your loved one. It means your loved one can get the maximum benefit from treatment, have time to plan what is important to them in their quality of life going forward, and gives you more time to get connected to existing resources and families who are going through the same thing.

**What's next, and critical, is making an appointment with your loved one's doctor as soon as possible.** Your loved one will probably feel most comfortable starting with their primary care physician and that will be easier for you – you already know who to call.

The doctor's evaluation should include the following: an examination of your loved one's medical history, mental status and mood tests, a physical exam, a neurological exam, and if necessary tests to rule out other causes of dementia-like symptoms (such as blood tests or CT scans.) They may refer you to a physician who specializes in the diagnosis and treatment of dementia.



## **HOW DO I GET MY LOVED ONE TO LISTEN TO ME AND GO TO THE DOCTOR?**

Remember how you felt when it sank in that your loved one might be facing dementia? Well, imagine how they feel as they start to notice it happen to them. In their eyes, going to the doctor for memory loss isn't just the signal of a diagnosis, it could mean their entire life changes when they walk out of that office. If you look at it through that lens, it helps to see that they may not just be stubborn, but scared. Here are some ways to convince them going to the doctor is the best next step.

**Start by asking them how they feel.** Be patient during this conversation and focus on giving them room to explain how they feel and sharing what you've noticed. Avoid authoritative tone and language like "I think you should." Instead, try, "I've noticed you have been having a hard time remembering (x,y,z)...what do you think?"

**Phrase the appointment as a simple "check-up."** Next, you can use a familiar practice – going to the doctor for a check-up – as a way to keep the conversation neutral. Let your loved one know that of course, only the doctor has the answers, and note that it may be something as simple as a medication change or nutrient deficiency. You can explain there are plenty of new medications that may help with memory, but they have to be prescribed by a doctor. Throughout this conversation, it's best not to use the word "dementia."

**If you're not able to make headway, ask your loved one's close friend or favorite relative to try the same techniques noted above.** Sometimes the message needs to come from someone other than the most involved caregiver.

**Ask your loved one to go to the appointment "as a favor to you."**

That makes it about their love and sense of duty to you.

**Use another health complaint as a reason to get an appointment scheduled.**

This requires calling the doctor's office in advance to express your concerns and plan for having a dementia-focused evaluation.

**If your loved one's memory loss is already advanced, tell them you have an appointment and ask that they come with you.** Again, this requires calling the doctor's office in advance to plan. Be sure to discuss how you'll shift the conversation to your loved one during the visit.

**As a last resort, you might call your loved one's doctor's office and ask them to contact your loved one directly to make an appointment.**

Sometimes that physician authority helps.

## What should I ask the doctor and bring to the appointment?

Coming to an appointment with prepared questions and clear descriptions of symptoms (with examples) helps a doctor conduct a thorough evaluation and eventually make a diagnosis.

*Here are things to ask and have on hand to make this visit what you need it to be.*

### What to bring:

- Another person you can trust. Hearing a diagnosis can make it hard to comprehend everything that comes after. Bring someone you can trust and specifically task them with writing down the minute details that the doctor shares.
- A list of past and current medical problems. Tell the doctor if other family members had medical issues that caused memory loss.
- All medications your loved one is currently taking (prescription and over-the-counter).

### What to ask: Initial visit

- What specific tests will you be performing to diagnose my loved one?
- What will each test involve? Will my loved one feel pain or be uncomfortable during testing? Will there be side effects before or after?
- When can we expect results to come in?
- If you don't think this is dementia, what else could it be? What is the plan for determining if it is one of those other things?

### What to ask: After diagnosis

- What kind of dementia does my loved one have?
- How will this dementia progress?
- What dementia treatment(s) do you recommend and why? What side effects can we expect?
- What dementia treatment (s) do you advise against and why? Will there be a time when those treatments are no longer effective, and how will we know?
- Can my loved one receive treatment at home?

### **WHAT IF THE DOCTOR DOESN'T SHARE MY CONCERN?**

No matter what, you know your loved one best and if you know that something is changing, they need you to be their advocate in getting the evaluation they deserve. Here are some tips:

- Ask the doctor if they plan to perform each evaluation step mentioned above (it helps to have each written down beforehand). If not, ask for clarity on the rationale and if the plan is to complete those steps at a later time.
- State your desire for transparency upfront. Let the doctor know you may be stepping into a caregiver role, which means you want, and need, to understand the full details of what is happening.
- If your visit with a doctor doesn't feel right, you can also ask your primary care provider to refer you to a dementia specialist, usually a neurologist. Of course, it may take more time to get an appointment with a specialist, but it often results in peace of mind.



# PART III: CARING FOR A LOVED ONE WITH DEMENTIA

*As dementia progresses, what should I expect?*

**Mild cognitive impairment (MCI):** At this initial stage, your loved one might lose things often, forget things and have trouble coming up with words.

**Mild dementia:** Your loved one can still function independently, but they will experience memory loss that affects their daily life, like forgetting words and where they are.

**Moderate dementia:** At this stage, your loved one will need more daily help. They may have increased confusion; more significant memory loss (including forgetting events in the distant past); need help getting dressed, bathing and grooming; have major personality and behavior changes; and have changes in sleep patterns, like sleeping during the day.

**Severe dementia:** At this most advanced stage, common symptoms your loved one may experience include: loss of the ability to communicate, need for full-time assistance with daily tasks, and a loss of physical capabilities, such as walking, sitting, and holding one's head up and, eventually, the ability to swallow, control the bladder and bowel functions and an increased risk of infections like pneumonia.

## **We have the diagnosis, now what?**

**Find a support group for yourself (online or in-person).** We understand – you're in solution-mode for your loved one and probably feel like there's no time to think about yourself. But, now is actually the best time – you're not wrapped up in new caregiving responsibilities yet and you can set up time for your care.

**Find a space where you can share what you're going through with people besides family and friends.** It helps ensure you're not holding in the emotions and frustrations you may be feeling (which are more than valid), so you're able to show up for your loved one. If you're not ready for in-person groups, there are also online options.

**Learn all you can about the specific dementia.** Ask your loved one's primary care provider or specialist to be clear about the following: the cause of this dementia, the key characteristics of it, how it will progress, treatment options and their side effects, and unique care concerns for their dementia. Also ask that they direct you to further resources either online, through specialists, or through support groups.

**Talk to family members that you can trust to be helpful and involved.** At this early stage, it's important for you to make decisions through the lens of what will help you reduce stress and divide responsibilities. That includes choosing who to initially share the news with and ask for support from. So, rather than immediately sharing the news with everyone, choose a smaller circle of family members and friends who you know will be understanding and a reliable source of support. You may not be ready to ask for help around specific care action items yet, but you can ask these folks to check in more often, spend some time with your loved one while you get out of the house, help you with care referrals or online research, or even telling the other members of your broader circle about the diagnosis.

**Talk to your loved one about their goals for treatment.** This step is often overlooked but might be the most important step you take. If you feel yourself spiraling into a list of to-dos and doctors are pushing for quick decisions on treatments, take a break and realize that before you make any plans, you need to know your loved one's wishes. That includes talking to them about if they want to know every detail about how their disease progresses or if they'd rather not; if they want as much treatment as possible or very little; what things they love to do and would never want to lose out on because of treatment side effects; etc. The Conversation Project offers a [step-by-step guide](#) on talking to loved ones with dementia or Alzheimer's about their wishes.

**At the next doctor appointment, spend time sharing your loved one's wishes. Then make a treatment plan together.** A doctor's job is to treat you. Your new job as a caregiver is to be the advocate of your loved one's wishes and ensure they are always considered when planning treatment. As the illness progresses, ask the doctor to always be clear about how new treatments will impact those goals.

**Get connected to services.** Ask your primary care provider if they can provide resources on local help services. That includes in-home help, adult day programs, and local support groups for both your loved one and you as a caregiver.

## **Talk to an elder care lawyer to determine which legal steps need to be taken.**

It's important to address legal needs as soon after the diagnosis as possible – that way your loved one can participate in the legal planning process while they are still able to make sound decisions. If your loved one is past that point, lean on your close circle and discuss these decisions with them.

Key steps to ask a lawyer about include:

- taking inventory of existing documents;
- making plans for finances and property;
- planning for future health care and long term health care preferences; and
- naming a health care proxy, the person who will make decisions for your loved one if they cannot do so.



We know everyone can't afford to consult a lawyer. If that's the case, there are free online legal guides, like this one from the Alzheimer's Association, to walk you through the legal planning process in detail.

**Make a financial plan.** Just because you may be the caregiver does not mean you automatically take on all of your loved one's financial burden. There are a number of programs and resources to help. But before you consult those, it's best to get a handle on your loved one's current financial standing. Priority tasks include:

- Identify costs of care. Divide up the tasks of investigating the following costs with your inner circle:
  - » Ongoing medical treatments and follow up visits
  - » Treatment costs for other current medical treatments
  - » Home safety modifications
  - » Prescription drugs
  - » Adult day services
  - » In-home services
  - » Full-time residential care services
- Research (or have a member of your inner circle research) existing government benefits that may provide help with prescriptions.
- Review your loved one's existing insurance policies to see if it may cover future care costs
- Investigate available veterans benefits (if applicable).
- Task a member of your inner circle with helping you complete regular financial duties, like paying monthly bills .

- Look into the following resources that may be available to your loved one to cover care costs:
  - » Medicare, Medicare Part D and Medigap
  - » Medicaid
  - » Insurance
  - » Employee or retirement benefits
  - » Personal assets (like property or investments)
  - » Veterans benefits
  - » Supplemental Security Income (SSI)
  - » Social Security Disability Insurance (SSDI)
  - » Community support services, such as meals on wheels, respite care and transportation services

**Develop a care team.** Think about this one as protecting yourself and your loved one. One way to think about your care team is your inner circle of family and friends + your loved one's medical team + community resources. Often it's best to have the following people involved:

- Family members, even those living far away
- Neighbors who can stop in and help with daily tasks
- Your loved one's primary care provider
- A volunteer from a community organization or church group



**Make a safety plan.** It's helpful to think about taking safety measures in your home as a way to give you peace of mind as a caregiver. Taking these steps now lets you know your loved one is safe, which can take some of the burden of providing constant oversight away.

- Evaluate your home or your loved one's home for hazards. Pay close attention to areas with tools, chemicals or cleaning supplies. Be sure to store these items in a secure place.
- Take small steps to avoid daily task injuries.
  - » Avoid serving food that is too hot;
  - » Install walk-in showers;
  - » Install a hidden gas valve or circuit breaker on the stove;
  - » Use appliances that have an auto shut-off feature;
  - » Remove plants or decorations that may look like real food;
  - » Install non-skid mats or strips on slippery surfaces;
  - » Remove prescription drugs and vitamins from counters and place them in a locked area.
- Take steps to reduce wandering. One preventative measure that is sometimes overlooked in efforts to reduce wandering is planning ways for your loved one to have structured activities and, when possible, physical activity, to reduce anxiety and restlessness. Both are major triggers for wandering behavior. Involving your loved one in simple chores like folding clothes or setting the dinner table are examples. Some additional steps you can take include:
  - » Place deadbolts high or low on doors that lead outside
  - » Avoid taking your loved one to busy places that are overwhelming, like a supermarket or the mall



## How do I take care of me, too?

Caregiving is often rewarding but undeniably stressful. Most caregivers have jobs and families in addition to the person for which they provide care. It's very easy to burn out and even become ill if you don't make it a priority to include yourself in your caregiving efforts.

- Don't feel guilty about taking time to care for yourself. You can't continue to care for your loved one properly if you burn yourself out or harm your health.
- Get a two for one. Use your caregiver tasks as a way to care for yourself. For example, schedule a checkup for yourself the same day as your loved one's doctor appointment.

Take naps and rest when your loved one rests.

- Use your benefits. See if your employer has a plan that helps employees find caregiver resources, such as community services, counseling and caregiver support groups. If your company has more than 50 employees, you may qualify for unpaid leave for work under the Federal Family and Medical Leave Act.
- Plan time to prioritize your health. Caregiving can put you under prolonged stress, and that makes healthy habits even more important. Make yourself sit down and eat at least three meals a day. Make time to exercise and get enough sleep.
- Take a break. Resolve to continue doing the things you enjoy, and that will recharge your batteries drained by caregiving. Relax in a warm bath. Read a book or listen to music. Spend time with friends. Or just let yourself be alone for a short time.
- Ask for help and give yourself permission to accept it when offered.
- Cut yourself some slack. Being a caregiver means making difficult decisions and learning new skills that may not exactly match your abilities or interests. Accept that there will be difficulties and setbacks, but don't criticize yourself because of them.



# HOW DO I KNOW WHEN MY LOVED ONE NEEDS HOSPICE CARE?

Hospice is care designed to meet the needs of those who are in the end stage of an illness.

Hospice care is advisable when your loved one has reached the point where managing his care exceeds your ability to provide the time and level of expertise needed to keep him safe, comfortable and as pain free as possible.

**When to Call Capital Caring?** In order for a dementia patient to meet the hospice eligibility criteria, Medicare regulations require a physician to certify that a patient entering hospice is likely to die of his or her disease within six months.

Common signs that the disease has progressed to a point where all involved would likely benefit from hospice care for dementia is when he/she:

- can say only a few words
- can no longer walk and may be bed-bound
- is totally dependent on others for eating, dressing and grooming
- shows signs of severe anxiety

You or your physician may request an evaluation from Capital Caring to see if hospice care for dementia is an appropriate option for care.

**What do I need to know about it?** The most essential thing to understand is that quality hospice care is a coordinated effort between you and the hospice agency or organization. Capital Caring's approach builds on what you already have in place – for example, the private home or other facility where your loved one is being given care, and the medical providers that they already have – by adding a team of hospice experts.

These personnel can range from our expert hospice physicians and nurses to certified nurse aides, dietitians and social workers. Working together, and with your own doctors, they provide care that emphasizes pain control and the ability of your loved one to live as independently and as fully as possible in the final stage of life.

*To learn more, please download and refer to our booklet on how to understand and make decisions about hospice care.*

**Call 1-800-869-2136 to speak with someone  
24 hours a day, 7 days a week**

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