

Dementia Guide *for Families*





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Caring for a loved one with dementia can feel overwhelming, but you don't have to do it alone. From understanding the diagnosis to creating a safe and supportive environment, this guide offers insights and practical tips to help you and your family navigate this challenging journey. While life may change, your loved one can still experience joy and connection in new ways.



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SECTION 1

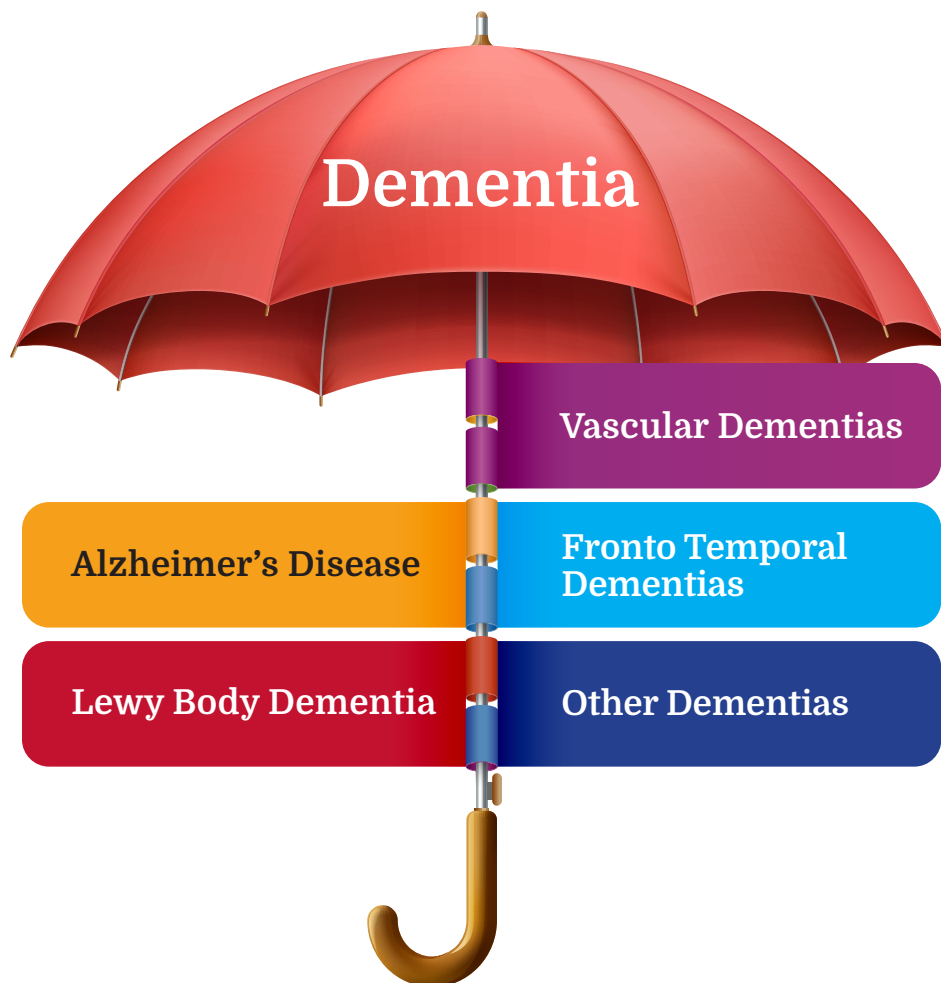
Understanding Dementia



Understanding Dementia

Dementia is a broad term used to describe significant changes in memory, thinking, or reasoning that interfere with daily life. It's important to recognize that dementia is distinct from the normal cognitive changes associated with aging. Rather than being a single disease, dementia encompasses a variety of conditions, each with its own specific causes and symptoms.

Much like how “cancer” refers to a group of related diseases, “dementia” serves as an umbrella term for several different types of cognitive decline. The most common and widely recognized form is Alzheimer’s disease. However, other forms include Lewy body dementia, vascular dementia, frontotemporal dementia, and dementia associated with Parkinson’s disease. Each of these conditions impacts the brain in different ways, leading to the symptoms we collectively refer to as dementia. Understanding the specific type of dementia your loved one has is crucial for managing their care effectively.





Common Warning Signs of Dementia

When diagnosing dementia, certain symptoms tend to be more prevalent and noticeable. Here are some of the most common warning signs to watch for:

- **Memory Loss:** Frequent forgetfulness, particularly of recent events or important dates.
- **Difficulty with Familiar Tasks:** Struggling to complete everyday tasks that were once routine.
- **Language Problems:** Trouble finding the right words or following conversations.
- **Disorientation:** Confusion about time, place, or familiar environments.
- **Poor Judgment:** Making decisions that are out of character or lacking in reason.
- **Difficulty Organizing:** Problems keeping track of items or managing complex tasks.
- **Misplacing Items:** Regularly losing things and being unable to retrace steps to find them.
- **Changes in Mood or Behavior:** Unexplained shifts in personality, mood swings, or increased anxiety.
- **Visual-Spatial Issues:** Difficulty judging distances, depth, or understanding visual information.
- **Social Withdrawal:** A growing tendency to withdraw from work, hobbies, or social interactions.



The Importance of Seeing a Doctor



If you suspect dementia, it's essential to consult a doctor. There are many types of dementia and a doctor can perform a thorough evaluation to diagnose the specific condition. Once diagnosed, it's crucial to consider Memory Care options to ensure the best support for your loved one.



What to Expect After a Dementia Diagnosis?

We understand that a dementia diagnosis is life changing for both your loved one and the entire family. Once diagnosed, there is a likelihood that you will experience a wave of emotions as you adjust to the news.

Those diagnosed, and their families, may experience any number of these common emotions once a diagnosis is confirmed:

- Anger
- Denial
- Depression
- Resentment
- Fear
- Isolation
- Relief



It's normal to experience a range of emotions after a dementia diagnosis, but it's crucial for your family to quickly seek out a supportive community to help you adjust. Just as important as the medical diagnosis is the emotional well-being of the entire family. The journey of finding the right medical care, Memory Care options, and emotional support for your loved one—and for yourself as a caregiver—will be ongoing.

Dementia often brings significant communication challenges, such as difficulty finding words, memory lapses, and reduced verbal communication, with more reliance on

gestures. These changes can be difficult to witness, but it's important to remember that any shifts in behavior are not intentional. Caring for someone with dementia is a long-term commitment, and finding the right living solutions will require patience and ongoing effort.



SECTION 2

Caring for a Loved One Experiencing Dementia



Caring for a Loved One Experiencing Dementia

Adjusting to life as a caregiver for someone with dementia takes time, and it's natural for this transition to impact many areas of your life. While your daily routine, your way of connecting with your loved one, and even your home environment may change, it's essential to remember that your loved one is still present. Although they may struggle with communication and memory, they can still find joy and meaning in life.

6 Things to Know About Someone with Dementia

- **I can still smell the flowers.**
I don't garden anymore, but I can still smell the flowers. Bring me some roses. This will remind me of my past.
- **I can still communicate.**
I can't talk the way I used to, but I can still communicate. Be patient as I try. This will help me feel connected.
- **I can still wash my face.**
I can't take a bath by myself anymore, but I can still wash my face. Assist me with direction. This will help me feel purpose.
- **I can still sing.**
I can't dance unassisted anymore, but I can still sing. Help me enjoy music. This will enrich my life.
- **I can still move my body.**
I can't walk unassisted anymore, but I can still move my body. Walk with me and support me if I stumble. This will help me feel engaged.
- **You are key to the quality of my life.**





Tips for Communicating with a Person Living with Dementia

Communicating with a loved one experiencing dementia can be challenging. Remember, the symptoms are taking over the person and the adjustment will take some getting used to over time.

Here are a few tips to help you communicate:

Realize Your Challenge

There will be good days and bad days.

Be Patient

Tolerate compassionately any delays or provocation.

Offer Reassurance

Listen attentively & empathize.

Minimize Noise

Noise can disturb and confuse.

Avoid Arguing

Do not contradict.

Use Non-Verbal Cues

Gestures, touch & facial expressions.

Be Precise

Avoid pronouns such as “they,” “he,” or “she.”

Keep It Simple

Make sure questions can be answered with yes or no.



People experiencing memory loss can still feel. Holding a hand, placing a gentle hand on the shoulder, or giving them a hug are all things you can regularly do to both connect and communicate with them. Also remember that this syndrome affects each person differently.

As you’re adapting to the diagnosis, you are also adjusting to how you interact with your loved one. Try not to make any assumptions and assertions about how he or she will communicate moving forward.

“Touch is a language seen by the blind, heard by the deaf and felt by everyone.”

MARY JUDD



What is Sundowning?

Behavioral changes will be common as the journey progresses. As a caregiver, you will notice that your loved one will periodically express some unwelcome fluctuations in behavior. A common behavioral change expressed by individuals with dementia is due to something referred to as sundowning.

Sundowning occurs as daylight changes into evening. At this time, many people living with dementia express restlessness, agitation, irritability, and/or confusion. This may continue into the night and the person may have difficulty staying in bed. These behaviors may also be triggered by the individual's environment and his/her inability to express those needs. For example, the person may be experiencing thirst, hunger, pain, or the need to use the restroom.



Strategies to help reduce sundowning:

- Avoid overstimulation.
- Establish an evening routine, like playing calming music or saying a prayer.
- Set aside time for relaxation or a nap during the day.
- Minimize noise and clutter.
- Offer a favorite object, activity, or snack as a distraction.
- Close curtains at dusk and turn on lights to reduce confusing shadows.
- Check if the person is in pain.



SECTION 3

Creating a Dementia-Friendly Home



Adapting Your Home to Support Quality of Life for a Person with Dementia

If you're caring for your loved one at home after a dementia diagnosis, it's crucial to design spaces that meet their evolving needs. A dementia-friendly environment will help them feel more connected and adapt to their new normal. As behaviors and mannerisms change, it's important to maintain a sense of independence, safety, and comfort in an environment that supports who they are becoming.

Dementia-Friendly Design

Creating a dementia-friendly environment involves thoughtful choices in lighting, color, and contrast. It's also important to incorporate familiar and meaningful objects that provide comfort and connection.

Here are four key strategies for optimizing lighting in your home:

1. Adjust Lighting for Vision Changes:

As your loved one's eyesight may be affected by dementia, it's essential to adapt the lighting in your home to meet their needs.

2. Maximize Natural Light: Use daylight as much as possible by keeping curtains open during the day to allow sunlight to fill the space.

3. Opt for Ambient Lighting: Choose table lamps or wall-mounted lights over harsh overhead lighting to create a more comforting, homelike atmosphere.

4. Align Lighting with Natural Cycles: Ensure that in-home lighting mimics the natural day-to-night cycle to support your loved one's circadian rhythm and promote better sleep.





Key areas of your home should be carefully adapted to meet your loved one's changing needs, including the kitchen, bathroom, outdoor living space (or garden), bedroom, and living/family room. Additionally, it's important to provide a private space where your loved one can have time alone. Here are some suggestions for making a few of these key spaces more supportive:

Bedroom

- Install blackout blinds to prevent confusing shadows.
- Consider removing mirrors to avoid potential distress.
- Ensure a clear line of sight to the bathroom.
- Use contrasting colors for lighting and switches to improve visibility.

Kitchen

- Install safety switches for both the stove and oven.
- Always keep the gas supply to the stove turned off when not in use.
- Use see-through cabinets to help your loved one easily find items.



Montessori for Dementia

Incorporating the Montessori model into your loved one's living environment is an excellent way to enhance their sense of self, create a meaningful space, and engage their senses. This approach helps build self-worth and fosters a connection to the outside world, despite the challenges of dementia.

The Montessori philosophy includes four key attributes:

- Enables individuals to be as independent as possible.
- Have a meaningful place both at home and within the community.
- Encourages them to accept themselves as they are and possess high self-esteem.
- Encourages your loved one to make meaningful contributions at home or in the community.

You can apply this philosophy in various practical ways, such as encouraging your loved one to set the table independently, fold towels or socks, brush the dog, or arrange flowers. These activities help them stay engaged and feel purposeful.



SECTION 4

Self Care for Caregivers



Self Care for Caregivers

Caring for a loved one with dementia can be physically, mentally, and emotionally exhausting. When the focus is on caring for someone else, it's easy to neglect your own needs. However, just like on an airplane, you must put on your own oxygen mask before helping others. The same principle applies here—self-care is essential. It's one of the most important yet often overlooked aspects of being an effective caregiver. To be the best caregiver you can be and to safeguard your long-term health and well-being, making self-care a priority is crucial.

Recognizing Signs of Built Up Stress

It's normal to feel stress while taking care of a loved one experiencing dementia. These feelings can be magnified if you're overwhelmed with other life matters.

It's important to recognize the signs that pent-up stress may be causing in your life. These signs may include:

- Headaches and/or body aches
- Disruption in sleep patterns
- Digestive issues
- Weight gain or loss
- Having a short fuse; being quick to anger or irritation
- Losing interest in activities or hobbies that once brought you joy
- Reliance on alcohol, drugs, or prescription medications



If not addressed, the implications of this stress load can be serious. The Family Caregiver Alliance reports caregivers experience higher levels of stress, anxiety, and depression. Studies also show that caregivers are less likely to seek regular medical care for themselves and experience twice the rate of chronic conditions, including heart disease, cancer, diabetes, and arthritis.



Self-Care Tips for Caregivers

As a caregiver, you cannot stop the impact of dementia on your loved one, but you can take responsibility for your own personal health and well being so that you don't neglect yourself while providing needed care. There are resources and tools available that can help ensure you take proper care of yourself.

Here are some tips we recommend you consider as you continue along this journey:

Reach Out for Support

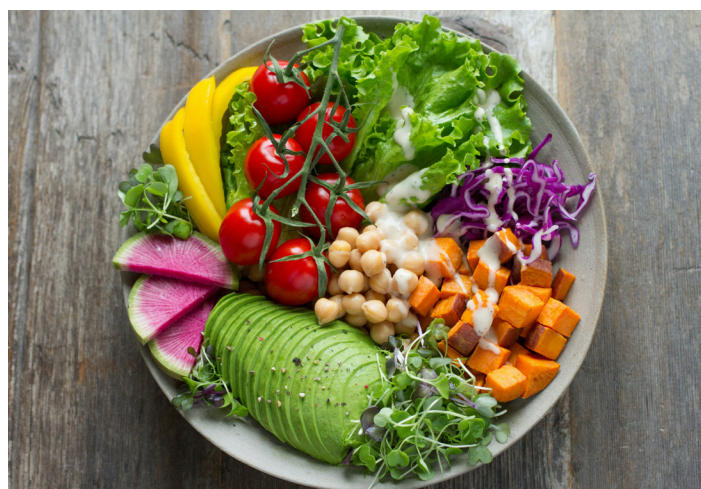
Asking for help can be challenging, especially when you feel the full weight of caregiving on your shoulders. Identify specific tasks that could lighten your load and reach out to a family member or trusted friend for assistance. You might be surprised at how willing people are to help, and giving yourself some extra breathing room can make a significant difference.

Stay Connected

Resist the urge to isolate yourself from friends and family. Make a conscious effort to maintain important connections and reach out to those in your support network. Consider joining a local support group or accessing community resources to help you process the changes and challenges you're facing. Remember, you are not alone—others in similar situations can offer valuable insights and strategies for caregiving and self-care. The more you connect, the more you'll learn and grow from shared experiences.

Prioritize Basic Health Habits

Maintaining regular eating and sleeping habits is essential, even when stress threatens to disrupt them. Sometimes, stress can lead us to neglect these basics or overindulge in them. Be intentional about nourishing your body with a balanced diet and getting enough rest. Not only will this sustain your energy for caregiving, but it will also help reduce stress for both you and your loved one.



Reestablish Old Routines

When significant life changes disrupt our daily routines, it's easy to lose touch with the activities that once brought us joy. Reflect on what you enjoyed before becoming a caregiver—did you go to the gym early in the morning? Did you have regular lunches with friends? While caregiving can be demanding, it's important not to completely sacrifice the activities that make you happy and fulfilled. Holding onto these routines not only provides a much-needed break but also boosts your motivation and well-being, making you a more effective caregiver.



Stay on Top of Your Health

While caring for a loved one with dementia, it's vital to monitor your own health as well. Keep up with regular doctor's appointments, stay current on vaccinations, and let your doctor know you're a caregiver. Openly discuss how you're managing and share any concerns. Remember, your health and well-being are crucial to your ability to provide care.

Utilize Respite Care

Taking regular breaks is essential for maintaining your physical and mental health as a caregiver. Just as businesses offer vacation time to prevent burnout, caregivers need time to recharge as well.

At Clark Retirement, we offer Respite Care, where your loved one can stay in a furnished suite and receive excellent care from our compassionate staff. They'll enjoy our activities and amenities while you take the time you need to rest and rejuvenate, knowing your loved one is in good hands.





SECTION 5

Assessing the Need for Memory Care



Assessing the Need for Memory Care

Deciding whether it's time for Memory Care is a common and challenging question for caregivers. Ask yourself: Is my loved one in need of more care than I can provide? Is my physical or mental health declining? Would my loved one benefit from being around others with similar experiences, where they can feel successful and form meaningful connections? These questions can help guide you in making the best decision for your loved one's care.

What is Memory Care?

A Memory Care community specializes in the well-being of the person "living with dementia". The goal is to provide the best "quality of life" possible for the person along their journey. This includes a Life Enrichment program where staff are trained in dementia and life enrichment activities. A Memory Care community can provide support for family with dementia education and caregiver support groups.

Common Signs Memory Care Could Benefit Your Loved One:

There are several common signs to keep in mind as you consider Memory Care as a viable option to support your loved one.

Alzheimer's, Dementia or Dementia-related Diagnosis

While occasional forgetfulness is a normal part of aging, consistently forgetting important dates, names, and tasks may indicate dementia or a related condition. If your loved one has been diagnosed with Alzheimer's,



dementia, or a similar condition, it's crucial to begin exploring Memory Care options. Staying at home during the early stages is often recommended, provided there are no significant safety concerns. Research shows that transitioning to Memory Care before the later stages of dementia can be beneficial, as it allows your loved one to build relationships with the staff and have some input into their care plan.

Safety Concerns

Memory loss can bring about new daily challenges. It's possible your loved one might go for a walk but forget where they were going or how to get home. Memory loss can also lead to more falls as people sometimes lose their habitual knowledge of where the curb ends or where they left an item around the house that might be a tripping hazard. If you are starting to grow concerned about your loved one's everyday safety, it's time to start discussing Memory Care.



Increased Health Issues

Memory loss can significantly impact your loved one's overall health. They may experience sleep disturbances due to confusion about time and may struggle to remember to take their medication or follow the correct dosage. Additionally, preparing nutritious meals can become difficult, leading to rapid weight loss and a weakened immune system. If you notice a decline in their health due to memory loss, it might be time to consider Memory Care.

Declining Living Conditions

Memory loss can also lead to a deterioration in your loved one's home and living conditions. Unpaid bills, cluttered spaces, and general disarray may become more common. Your loved one might forget to go grocery shopping, take out the trash, or maintain their personal hygiene, such as showering or brushing their teeth. If you observe a decline in their living conditions, it could be a sign that they would benefit from the additional support and structure provided by Memory Care.

Memory Care at Clark

At Clark Retirement, our philosophy on dementia care is to focus on the possibilities while creating a safe atmosphere so residents can thrive.

Clark is the first **Life Plan Community** in the United States to adopt the International Montessori for Aging and Dementia program. Our program is led by certified Montessori practitioners, who empower residents with memory loss to lead as independent and purposeful lives. Clark does so by creating meaningful routines, activities based on interest, and an environment with memory cues and supports. Our program is supported by Music Therapy, Equine Therapy, IN2L computer programs and Eversound headphones for hearing difficulties.

If you think your loved one could benefit from a Memory Care community, contact our sales counselors at marketing@clarkretirement.org or **616-278-6520**.



Additional Resources:

Clark Dementia Resources Video Library

<https://clarkretirement.org/dementia-resources/>

Family Caregiver Alliance

<https://www.caregiver.org/>

Dementia Institute

<https://dementia-institute.org/>

Dementia Support Groups in Michigan

https://www.alz.org/gmc/helping_you/support_groups

Clark is a leading senior living community in Grand Rapids, Michigan offering a range of living options and services including assisted living, Memory Care, skilled nursing, respite care, independent and retirement living.

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