



GUIDE TO LIVING

WITH DEMENTIA

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DEMENTIA...

it creates repercussions for everyone within one's circle of family and friends, who all come to be "living with dementia." While this can feel like an isolating and helpless situation, in truth, the diagnosed and their loved ones do have access to powerful tools to help them build and adapt to their "new normal." Welcome to your opportunity to learn these tools!

Rather than provide you with medical information, this guide offers sensible, realistic, no-nonsense help. Here you will find practical tips that can be put into everyday action. You'll find handy resources for real-life dilemmas and information you can depend on and make the most of—for your particular family and your particular situation.



First, let's be clear on these 4 points

- As with any chronic condition, the progression of dementia can't be neatly broken into discrete points. *This means one may not personally experience some of the symptoms.*
- Changes caused by dementia occur differently for each individual. *There is no set pattern to anticipate.*
- The symptoms referenced within this guide as early (mild), middle (moderate), and late (severe) stage dementia are not absolute indicators of that particular stage. *For instance, if a diagnosis is early dementia but symptoms relate to those listed as middle stage, this does not mean the condition has progressed.*
- Be sure to consult your physician if you have questions or concerns about a diagnosis. *Let your physician know about any changes; simple medication or lifestyle adjustments can make a big difference.*

If you have dementia and are reading this guide...

We know that some reading this guide may be living with early stages of dementia. The scenarios outlined are only examples and may never apply to you. We sincerely hope we do not offend you with some of the descriptions that follow and that you will share the information here with family and friends to help them be supportive care partners. Well-informed and equipped caregivers can minimize some of the worst case scenarios that arise when a family finds itself living with dementia.

WHEN THE DOCTOR SAYS “DEMENTIA”

Dementia itself is not a disease. Rather, it refers to a set of symptoms that describe a condition. This condition, in turn, relates to a person’s ability to function compared to how they once did. Dementia is often associated with language difficulty, memory lapses, disorientation, poor judgment, and difficulty completing daily care routines such as dressing, eating, or hygiene tasks. Dementia results from a variety of factors, including inadequate oxygen supply, trauma to the brain through disease, stroke or head injury, and other causes.



- The most common cause of dementia is Alzheimer’s disease. Alzheimer’s origins are unknown. The disease damages and kills brain cells. Alzheimer’s is not a normal part of aging, but risk does increase with age.
- The second most common type is vascular dementia, which results from a series of strokes within the brain. These strokes can be so tiny that the afflicted person isn’t even aware of them. Cumulatively, though, they destroy brain tissue to a significant extent.
- Other common causes of dementia include Lewy Body disease, head trauma, Huntington’s disease, Wernicke-Korsakoff syndrome, and Pick’s disease.

THINK OF DEMENTIA as gradual and progressive brain damage due to disease. This brain damage steals one’s power to think and interact with the world.

A quick clarification for families

Dementia is not a mental illness.

Although dementia can include symptoms similar to a mental illness such as anxiety, compulsive acts, social inappropriateness etc., these result from a person experiencing physical, emotional, or environmental changes, not because they are mentally ill.

Dementia is not a personality disorder.

Personality disorder refers to a mental illness that is characterized by deep-rooted incomplete patterns of behavior and personality.

Understand that dementia never stands still. Deciphering a person's needs requires nonstop calculations and calibrations.

The frustration of dementia includes the fact that you can zero in today on what your loved one wants or needs, but the same clues may not apply tomorrow or the day after. A task your loved one easily accomplished two days ago may now agitate her. You can try your best to interpret subtle signs of fear, but these tenuous signs can morph before you're able to grasp them.

Simply put, you cannot stay one step ahead; you have to continually adjust your expectations. You won't get a chance to say, "Okay. This is how it is. I can handle it," because "how it is" changes. There is no set pattern of change in dementia—the disease progresses at different speeds and in different ways from person to person.

As much as you may feel it is noble to serve as your loved one's only caregiver, know this: Unless you are educated about her disease, are experienced as a dementia caregiver, and have an objective "third-party" perspective (which isn't possible when you know someone well), it is reckless to assume this caregiver role alone without outside assistance. It is akin to a person having a painful bone fracture and someone with no medical background attempting to treat it. Your best course of action—for your loved one, for her circle of family and friends, and for you—is to seek support from a third-party professional.

Daily interactions and discussions between you and your loved one (What once was effortless can become exhausting!)

We used to communicate just fine. Why can't I get through?

Dementia shreds communication. Your loved one may be unable to locate the words wanted, leaving you wondering what he is trying to say to you. And your loved one may not be able to process the words you're using, leaving him unsure about what you're trying to say to him.

The next step may be nonverbal:

When someone can't make sense out of what he sees and hears, he can become scared. Sometimes this will make him lash out in anger or embarrassment. He may sense your own distress and not know how to act. And you may not know which nonverbal techniques to use to address his concerns.

It's as if your loved one is increasingly replacing usual communication with a "foreign language." You can pick up basic phrases to keep up. But unless you learn the nuances and intricacies of this "new language," your loved one will misinterpret your message—and you'll become frustrated that you can't translate what he's telling you.

When your loved one

says something odd... some part of his brain most likely failed to perform correctly;

behaves oddly... it's either

- a frantic attempt to communicate a real and immediate need, or
- it reflects a comment his brain isn't allowing him to communicate verbally.



COPING TIP

It is important to remember that correcting your loved one will not rehabilitate the brain damage caused by his disease. One of your most difficult challenges lies in accepting his new communication pattern.

Two points to keep in mind regarding the exchange of ideas and feelings

First, it's crucial to know that the human brain's emotional memories are more resistant to dementia than are its factual memories.

Here's what you might encounter as a consequence

Has your loved one ever seemed upset with you for no apparent reason? People with dementia often forget the circumstances that caused strong feelings, but remember those feelings well after the incident. So if Mom reacted indignantly last

week to your offer to help her with something, that resentment can stay around long after she remembers why she was displeased with you in the first place. Keep in mind that this is not an attempt to mistreat you.

Second, it's vital to realize that emotional memory may or may not be affected along the course of dementia.

What you might find as a result

Dementia produces inconsistent behaviors within the same week or even the same day. Similar to a fading fire sparking and flickering unpredictably, the brain's neurons can fire and achieve connections erratically and randomly. Brain tissue damage to the emotional memory can cause your loved one to feel embarrassed when he can't communicate a pressing need to his closest family and friends.

The person with dementia can't prevent or control any of this, of course. But family and friends instantaneously try to place comments and behavior in the context of their longtime relationships. It's human nature.

EMPATHY TIP

*Imagine yourself in the dentist's chair, mouth numbed and filled with cotton rolls. Suddenly, you experience a sharp pain, or perhaps you need to use the restroom. You try to speak, but even you can't understand your words. If you point to your mouth, the dentist will probably guess "pain" rather quickly. But how will you let him know you desperately need the restroom? And how long will it take him to guess? **That's exactly the frightening, embarrassing, panic-inducing situation your loved one may experience.***

EMPATHY TIP

Respect comprises a fundamental part of our shared humanity. People diagnosed with dementia—from the very early stages, to those too ill to read this guide—all recognize when they're being treated with respect and when they're not.

It becomes easy to associate any communication shortcomings with those of a temperamental toddler learning to speak. This might cause you to behave in a way that condescends or demeans your loved one. Remember, he is still an adult with a lifetime of knowledge and experience, and he deserves your respect.



SOME TIPS TO HELP YOU COMMUNICATE WITH YOUR LOVED ONE

- Pay attention to your posture and facial expressions. Your loved one will begin to carefully watch your body language, tone of voice, and facial expression to help her “interpret your intentions.” If you seem impatient or upset when you tell your loved one that it’s time for breakfast or it’s time to shower, she may believe that you are angry with her and refuse to cooperate.
- Make good eye contact while looking friendly and relaxed.
- Speak slowly, clearly, and simply, but never use “baby talk.” Use concrete terms without sounding “bossy,” and give one instruction at a time. “Breakfast is ready—let’s go eat.” “Your shower is ready—let me help you.”
- If your loved one doesn’t respond, wait a few moments before trying again.
- Pay attention to nonverbal cues you are giving and receiving.
- Where appropriate, add gestures to match your words. “Mirroring techniques” help a person understand more quickly. When you want your loved one to brush her teeth, make the motion of brushing as you say, “Brush your teeth, Mom.”
- Be patient. Rushing will only frustrate you both.
- Don’t sweat the small stuff! If your husband will not shave before breakfast, maybe he will after dinner. If your wife wants to sleep in her clothes, it won’t cause her harm. If your brother calls you by the wrong name, answer him anyway.



Communication issues to be aware of as dementia progresses

Early stage (mild)

- Can't find the right words to name things or to complete thoughts
- Scrambles sequence of events when relating a story
- Speaks of past events as if they are currently taking place
- Can't remember what was just said
- Has difficulty following directions
- Short term memory is affected; may repeat questions and stories
- Makes multiple phone calls to a family member to ask about appointments, people, places, etc.
- Becomes suspicious and makes paranoid or accusatory statements
- Becomes defensive if corrected or if his "reality" is challenged

Middle stage (moderate)

- Confused if you talk fast or use slang, or if you use abstract ideas or offer too many thoughts or choices
- Needs more time to respond to others or to join conversation
- Becomes frustrated if more than one person talks at the same time
- Begins to use substitute words or use unorganized sentences
- Is often reduced to yes/no responses out of fear of making mistakes "in public"
- Makes inappropriate, odd, or impolite statements (dementia erases lines not crossed in "polite company")
- Repeats questions and stories
- Sings frequently or speaks in rhyme
- Is prone to fabricate forgotten details

Late stage (severe)

- Speaks 1 to 6 words a day
- Uses words that make no sense, or may just be sounds
- Repeats what's been said rather than responding
- Responds to nonverbal communication: music, sound, touch, and visual stimulation
- Communicates needs nonverbally through behaviors, facial expression, and sounds

Use this list as examples of issues you may face. Only a medical professional can diagnose the existence and severity of a memory impairing disease.



PRACTICAL WAYS TO HELP YOUR LOVED ONE AROUND THE HOUSE

A diagnosis of dementia doesn't automatically mean that someone cannot manage his own life. But as the dementia changes, adjustments in the environment can help him remain independent as well as safe. If you're not sure whether or not your loved one needs any changes listed below, consider contacting a care professional for an assessment and guidance.

For your loved one's home environment

- Monitor noise levels; be aware that hearing aids magnify background noise and people with dementia may not be able to balance these sounds. Too much noise causes increased confusion, anxiety, and overstimulation—which, in turn, can cause behavior issues. Even television can be overstimulating.
- People with dementia may forget to turn on a light; be sure there is ample lighting, especially in bathrooms. Minimize glare from windows and limit shadows. Consider motion-sensor lights and night lights throughout the house.
- Lower the temperature setting on the water heater to avoid burns. People with dementia lose the ability to judge temperature.
- If your loved one still uses the stairs, make sure the handrail is secure.
- Look for and remove any tripping hazards.
- Install solid colored carpet and use furniture with limited patterns.
- Colors with considerable contrast are easier to see; if the bed pillow is white, for example, use blue sheets.
- Replace glassware with plasticware (don't forget the drinking cup in the bathroom).
- If possible, have your loved one's bedroom located on the first floor.
- Be aware of balconies and windows—changes in depth perception and poor judgment can result in falls. Remote Care Technology can be utilized to alert you if your loved one opens a door, window, or enters an area you feel should be supervised.

- Firearms should be removed from the premises. Even if they're locked away, they pose a risk.
- Look for gadgets to help your loved one: devices that alert people to sounds such as the doorbell or phone, devices that help with vision such as clip-on lights or magnifiers, and devices that make gripping flatware or jar lids easier. Refer to stores or catalogs with products for the sight- or hearing-impaired, for the disabled, for those with severe arthritis, etc.

Balancing stimulation and rest proves critical, because the physical environment itself influences how people with dementia think, feel, and interact. A crowded or noisy room tends to increase anxiety and agitation; the same holds true for environments that are too quiet, too bright or dark, or too extreme in temperature.



UNDERSTANDING BEHAVIOR ISSUES

You've probably heard about or personally experienced some of the disturbing behaviors that can be part of dementia. These behaviors range from strange to embarrassing to dangerous. Influencing your loved one's ability to cope are the following:

- Fear of dementia can cloud communication and initiate problematic behaviors. Your loved one may be afraid when people and things don't seem familiar or when she's not able to remember how to do something.
- Frustration can occur from "sensory overload." Your loved one can feel disheartened, not able to comprehend what's going on in her immediate environment. She may become anxious and respond abruptly in an attempt to regain her composure.

- Loss of self can take place because dementia slowly erases identity and self-worth. People want to recover a sense of self but don't know how. Despair and anger can surface as a result.
- Indifference can be brought on either by the person trying to withdraw to handle life; or brain tissue damage may be at fault. Movement and activity should be directed toward her comfort level to help prevent this withdrawal.
- Irritability refers to a person with dementia exhibiting extreme impatience, throwing things, or yelling. Such behavior is usually a sign she can't understand the current situation. She may become fidgety or upset without being able to say why. These reactions could be from brain damage changing and progressing. Or she might be worried because she's not sure how she "should" be behaving. Perhaps she may be sensing your own nervousness.



PRACTICAL WAYS TO HELP YOUR LOVED ONE IF BEHAVIOR ISSUES ARISE

You can help by reassuring him or by redirecting his focus—for instance, asking him to help you complete a task. Most importantly, if your loved one is very upset, it's better to back off and allow him time to calm down before attempting any other activity or conversation. Remember: Never scold, correct, argue, or attempt to reason with your loved one. These responses are counterproductive and hurt relationships. Have compassion and remember that this certainly isn't what your loved one thought his retirement or golden years would bring.

Simple things to consider when behaviors arise, include:

- Checking to see if clothes are uncomfortable
- Finding out if he needs to use the bathroom
- Assessing if he is hungry or thirsty
- Ruling out side-effects of possible medication mismanagement
- Considering if he is just not feeling well today



DELUSIONS, HALLUCINATIONS AND CATASTROPHIC REACTIONS

Be aware of these particular situations that blur perception and reality

Delusions are untrue notions that a person holds firm. Sometimes delusions are connected with the person's past, twisting the factual with the nonfactual. A person with dementia can accuse others of stealing or lying, or viciously blame herself for her illness.

For instance, Dad tells you someone stole his eyeglasses and demands that you tell him who did so. To the person experiencing a delusion, items that have been misplaced seem "stolen." You must control the urge to say, "Who would want your old glasses? For the umpteenth time, Dad, you set them on that table." Instead, offer to help find the glasses.

Hallucinations refer to someone seeing, hearing, or smelling things that aren't really there. Reactions to hallucinations range from delight (Mom sees her beloved cat from 30 years ago) to terror (Mom hears an intruder breaking windows).

A **catastrophic reaction**—an inappropriate reaction to something that seems inconsequential—may occur if you directly challenge a delusion or hallucination. Catastrophic reactions can happen when the person with dementia doesn't feel well, feels rushed (perhaps she doesn't quite understand what she's been asked to do), or needs to think about too many things at once. The more upset the person becomes, the less she'll be able to think.

The best way to help a person experiencing delusions, hallucinations, or catastrophic reactions:

Don't argue with her reality. Doing so is like holding a book in your hand and insisting it's an apple; it will only frighten and confuse.

Remember that you don't have to agree or disagree. You can simply validate the person's feelings. Many families find that calmly using a chosen phrase works well: A daughter might say, "I'm listening, Dad"; a niece might stick with, "Okay, Uncle, I will take care of that."



SUNDOWNER'S SYNDROME

Some people with dementia display increased behavioral problems in the evenings. After an entire day of living through the exhausting effects of the disease, the person with dementia is often fatigued and sad. He may cope by wandering around the home, trying to leave, becoming argumentative, refusing to eat and resisting care routines.

A few helpful tips for dealing with Sundowner's Syndrome:

- Plan the day so that simpler activities are accomplished in the late afternoon or early evening.
- Keep a variety of quieter tasks available.
- Turn on additional lights as the afternoon progresses into evening.
- Allow your loved one to wander to release physical stress and energy. Keep walkways and hallways clear of obstacles that could cause a fall.
- Provide a rocking chair, which produces a soothing motion.
- Alert neighbors that your loved one may wander, and have a plan of action ready.
- Discuss behavior with your physician—he may need to adjust medication times and dosage.

SELF-HELP FOR THE CAREGIVER

It's inescapable: You and your loved one share a history together. Neither of you can attain a professional distance of neutrality or detachment.

Compare these two scenarios.

A woman you've just been introduced to for the first time accuses you of standing her up for a business meeting. She's furious with you.

No doubt, you'd be shocked and wonder how in the world you could have scheduled a meeting with someone you don't know. Ultimately, you would manage to handle the situation without finding it especially difficult to separate her behavior from your reaction to it. It is easy for you to compartmentalize her inappropriate reaction because you have no emotional connection to her.

Now, let's say your loved one makes a similarly erroneous accusation and is just as furious with you.

You'll inevitably feel some level of panic, some degree of responsibility for her behavior. It will not feel as natural to have a calm, detached response to someone you care for. You will be deluged with questions and doubts and worries ("Why does she think that?" "How can she be so mad about something that didn't happen?" "She never acts this way around my brother." "Does this mean that soon, she won't even recognize me?" "How can this be happening?") The barrage of uncertainties and fears will not permit you an objective stance. It's not your fault; it's because you're human and you care.

Your loved one may make statements or comments that are funny, sweet, or innocent, but she may make emotionally-charged and alarming claims that mingle fact with fiction, as in the above scenario.

A DIAGNOSIS of dementia means that a person changes gradually but radically. What is essential to realize is that no one can separate a person they've long known as vital and healthy from the person they now see as declining unpredictably but surely.



Remember, no matter how hard you try, you can never separate your emotional connection with your loved one from her irrational behaviors.

Note your immediate gut reaction to some typical accusations a loved one may make:

“You think that just because you come to see me, you can steal my money.”

“You’ve never been good to me.”

“Why in hell would you fix me meatloaf? You know I hate meatloaf.”

“I know you’re just waiting for me to die. You don’t care about me.”



Was your impulse to respond with logic?

Here’s a better way—the 5 “R’s”

- 1. Remain** calm. Don’t argue or try to reason. Take a deep breath before you act.
- 2. Respond** to feelings. Validate how your loved one seems to be feeling at the time.
- 3. Reassure.** Remind her she is safe and cared for.
- 4. Remove** yourself physically or distance yourself psychologically for a moment to regain your composure.
- 5. Return** fully to the situation when your loved one begins to calm down.

KEEPING YOURSELF HEALTHY SO THAT YOU CAN CARE FOR YOUR LOVED ONE

Statistics report that people caring for those with dementia suffer from depression twice as often as caregivers of persons with other illnesses. Family caregivers of people with Alzheimer's disease suffer illness more often and typically request assistance least often.



Sometimes the pressure of caring for elderly parents or persons with dementia can lead to stress. You begin to feel overwhelmed and unable to cope. These are physical, emotional, and behavioral warning signs of stress. Over time, stress can affect the body's immune system, and illness can result.

Warning signs of caregiver stress:

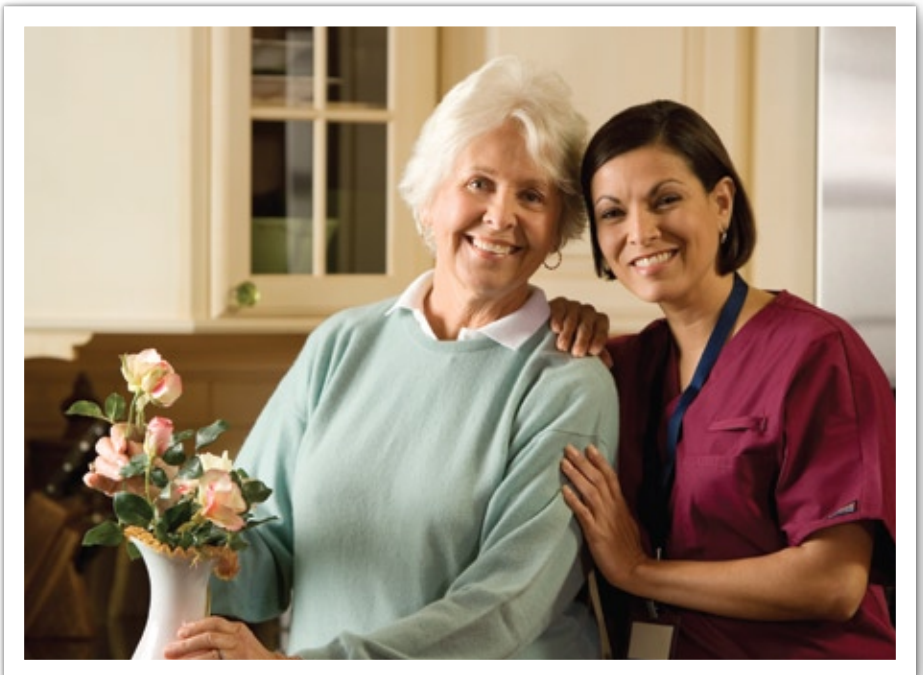
- Anger or sadness
- Inability to concentrate
- Unproductive worry
- Frequent mood swings
- Stooped posture
- Sweaty palms
- Tension headaches
- Neck pain
- Chronic back pain or fatigue
- Weight gain or loss
- Problems with sleep
- Over-reacting or acting on impulse
- Using alcohol or drugs
- Withdrawing from relationships

RECOGNIZING CAREGIVER BURNOUT

Burnout—physical, emotional, and mental exhaustion—can occur when stressors become overwhelming. Stress and caregiver burnout are a leading cause of families moving their loved one into a residential facility.

Symptoms of caregiver burnout include:

- Withdrawal from friends, family, and other loved ones
- Loss of interest in activities previously enjoyed
- Feeling blue, irritable, hopeless and helpless
- Changes in appetite, weight gain or loss
- Changes in sleep patterns
- Feeling sick or suffering illness often
- Thoughts of wanting to hurt yourself or the person you care for
- Irritability



Are you burning out?

Read each of the following items and rate how often the symptom is true for you. The scoring runs from 1 to 5 with 1 being **never** or **rarely true**, and 5 being **usually true**.

Add up your score at the end.

I feel tired even when I've gotten adequate sleep.....	<input type="checkbox"/>
I can't concentrate on work.....	<input type="checkbox"/>
I feel sad for no reason	<input type="checkbox"/>
I feel frustrated	<input type="checkbox"/>
I am irritable and snap at people.....	<input type="checkbox"/>
I avoid people at work and at home.....	<input type="checkbox"/>
Social activities are a drain	<input type="checkbox"/>
I have trouble sleeping due to worry	<input type="checkbox"/>
I feel sick more than I used to	<input type="checkbox"/>
I don't have much to look forward to	<input type="checkbox"/>
My attitude is "why bother?"	<input type="checkbox"/>
I often get into conflicts	<input type="checkbox"/>
My job performance is not up to par	<input type="checkbox"/>
Communicating with others is a strain.....	<input type="checkbox"/>
Feelings about care giving interfere with my life.....	<input type="checkbox"/>
My efforts feel pointless	<input type="checkbox"/>
I worry about my loved one all the time	<input type="checkbox"/>
Total Score.....	<input type="checkbox"/>

Scoring:

- 17-34: You're managing your stress well.
- 35-51: You're at moderate risk for caregiver burnout. Take preventive action such as practicing coping mechanisms.
- 52-68: You're at high risk for caregiver burnout. Seek out and utilize family and community support systems.
- 69-85: You have reached a critical stress level—a threat for harm to self or others. ***Seek professional assistance immediately.***

THE FUTURE DOES HOLD PROMISE

Science and medicine continue to search for treatment and prevention options. Medical breakthroughs and advances occur daily. Visit alzheimersassociation.com for the most current studies.

Your local chapter of the Alzheimer's Association has a lending library with books, videos, and CD's available for you to learn about dementia and Alzheimer's disease and how to care for someone living with it.

The Homewatch CareGivers website also provides a wealth of educational articles to support you and your loved one.



Homewatch CareGivers®



At Homewatch

CareGivers we're not just caregivers, we're an extension of your family. We offer the comfort and security that allow our clients the freedom to remain in their own homes. Homewatch

CareGivers offers a

variety of services that complement your family member's need for independence and quality of life. From transportation assistance to comprehensive personal care, let our family care for yours.



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