



Are you worried about a loved one's health?
Do you have concerns about caring for them?
Are there more questions than answers?



“Top 10” Questions in
Caregiving for Dementia

It's overwhelming when someone we love ages, suffers from memory loss, or is unable to do what they formerly could. We're here to help.

We've been serving Seniors and their families for many years and have observed some common questions related to the issues of aging, illness, memory loss, and dementia.

Today there are 18 million Americans caring for family members who are 65 or older. People are living longer, hospital stays are shorter, health care needs are mounting, and the complexity of caregiving is increasing.

The American Psychological Association states. "While it may be tempting to go it alone when caregiving, research shows that people who reach out for help fare better". Resilience research identifies that having someone with whom to share your story will help relieve the stressful impact of caregiving.

At Barrington Behavioral Health & Wellness (BBHW) we believe that no one should travel alone on their life journey. Trained psychologists and social workers partner with the patient, the caregiver, the family, and facilities where our patients live at any stage of the process.



It's never too late, or too early, to reach out for help. We assist families and are well acquainted with the process and resources that make caregiving easier.

This booklet will address the “Top Ten” Questions in Caregiving

1 ***How do I know when memory issues are a problem to be concerned about?***

Memory loss is something talked about lightly when we age, but how do we know when to be concerned? Forgetting that your glasses are on top of your head or not recalling if you locked the door can be typical as we age. When forgetfulness, confusion, and problems with daily living become consistent, it's time to reach out for help.

Memory Decline:

Can fall into three different stages though sufferers may exhibit symptoms from any of the stages simultaneously.

Early Stages

- Forgetting recent events
- Difficulty with daily tasks
- Problems with word retrieval
- Difficulty with simple math
- Forgetting names of familiar people
- Confusion & disorientation
- Poor concentration
- Finance Mismanagement
- Personality changes
- Problems with vision

Middle Stages

- Repeated questions
- Getting lost in familiar areas
- Changes in normal routines
- Confusion between night & day
- Shifting moods
- Increased dependence on caregivers
- Forgetting an item's location
- Inability to recall personal history
- Irritability or onset of aggression
- Sleep issues
- Falling frequently
- Appetite changes, dramatic weight loss
- Paranoid thought patterns (thinking misplaced items were taken)
- Unsafe driving
- Wandering may begin

Late Stages

- Mismanagement of medications
- Visual disturbances
- Disorientation to time or place
- No longer recognizes loved ones
- Confused speech
- Regressive behavior to earliest memories
- Requires around the clock care
- Difficulty swallowing
- Requires walking assistance
- Incontinence

2 The Value of Memory Testing

A Neuropsychologist is trained to understand and identify the cognitive functions of the brain and to use Neuropsychological tests to evaluate brain function.

The evaluation can include intelligence, executive function (ability to plan or conceptualize), language, attention, memory, sensorimotor functions, mood and emotion, and personality style. The neuropsychologist and



patient meet and perform a series of oral and written tests that conclude with an initial diagnosis. A copy is forwarded to your medical doctor and insurance and Medicare Part B covers a large portion of the cost.

Having a Neuropsychological evaluation (memory testing) performed early is highly recommend as the results will serve as the baseline of comparison as the progression of dementia occurs. Many families adapt to subtle changes in the patient and respond only when a crisis occurs. We suggest not waiting for the crisis. Early intervention allows for enhanced options, more preparedness, and resources for the patient and family care.

3 *My loved one has been diagnosed with Dementia now what?*

Education is critical, knowledge is power. Get an understanding from professionals of the type and stage of dementia that has been diagnosed and what it means for you and the patient.

It's important to review local resources available to caregivers. There's a growing body of research providing information for patients and their families. Many communities offer local services to assist the caregiver.

Be prepared for when a loved one can no longer care for themselves. It's important to appoint a Power of Attorney (POA) for health care & finance. This empowers a trusted person to make financial and health care decisions on their behalf. An Elder Law Attorney can assist you with this.

It's important to understand your own reactions to the diagnosis and behavior of your loved one. Acknowledge that this is a life changing illness. Take time to adjust to how the illness affects you, your loved one, and other family members. Some families may experience relief at the diagnosis as there was suspicion of a problem for some time. Others may be surprised and require significant time to process the impact on their lives. A common feeling is "This is not what we planned". Recognize this period as a grief process.

The stages of grief

The stages of grief can be applied to any diagnosis or significant life change. We adapt in stages, although these stages are not linear. You or your loved one may be at different stages throughout the process. It's not uncommon to go back and forth between these stages.

Shock: "how could this be?" "this can't be happening!"

Bargaining: "if only . . . , what if . . .?"

Anger: "why them, why now?" "this isn't fair!"

Sadness: deep heartbreak, depression

Acceptance: settling into a new reality

Acceptance requires courage and grace to recognize "what is" and what can't be changed. We give up the fight against change and look for the resources to cope and find meaning and purpose in the experience.



Recommended:

- Increase your knowledge base
- Take advantage of local resources
- Get Power of Attorney (POA) for health care & finances
- Share diagnosis with family (don't keep the secret)
- Get support for yourself with a therapist

4 *How will things change?*

Understanding Dementia in Your Loved One

Your loved one looks the same, so it can be difficult to accept they are not the same on the inside. Many families compensate for their loved ones as they decline because family and friends continue to think of that person as a functional adult, able to hold conversations, manage day to day responsibilities, and utilize a degree of logic in decision making.

Cognitive change can happen quickly as in the case of stroke or traumatic brain injury. More commonly, it occurs gradually as in Alzheimer's dementia. This slow progression further enables a family to deny that the person is not functioning at the same level. Of course, the normal aging process causes all of us to slow down. The dementia process is a disease state that progresses at rates faster than normal aging.

Dementia is an overarching term. Alzheimer's is just one type of dementia. It is a cortical dementia, which means it begins in the cortex of the brain where we have memory and language abilities and it spreads from there to other parts of the brain. Families often note that the person's short term memory is poor, but they can recall in detail events that occurred much earlier in their lives. This is because with Alzheimer's, memory deteriorates backward through the person's lifetime, starting with short term events such as a recent conversation. Each type of dementia progresses and manifests differently. Overall, it's memory that is primarily affected.

For caregivers, family and friends there can be challenges in time management and increased stress levels as you take on more responsibilities anticipate and prepare for eventual decline. Educate yourself so you know the stages of dementia. This will help increase your understanding and reduce frustration. Keep the problem manageable.

In the **early stages** of dementia patients may experience problems with word retrieval. They might not remember something they just looked at or read. They might forget simple tasks like making coffee or walking the dog. Tasks at work or negotiating social settings may become anxiety

producing. Losing or misplacing valuables and having trouble planning ahead are common.

Caregivers, families and friends may begin to experience frustration or annoyance with your loved one. If they're undiagnosed, lacking confirmation, you're likely to attribute the changes to other factors. You may start to behave differently toward your loved one by being more "helpful" or become more irritated and distant.

A baseline evaluation is necessary in order to be able to assess these changes and determine if a dementia presenting itself. If it has not yet been performed, this is a good time to get a baseline evaluation.

In the **middle stages** of dementia your loved one may begin to forget important personal history or information. There might be confusion about time and day, forgetting one's address or phone number, or being socially inappropriate in a given situation. Changes in behavior and personality (i.e.: suspiciousness or paranoia) can begin with compulsive or repetitive routines. There may be changes in sleep patterns and possible problems controlling bladder functions.

Noticing these changes usually causes great concern. Forgetting to take medicine, marked personality changes, and obvious confusion can create worry, fear, frustration, annoyance, and alarm. Family members may begin to compensate for their loved one's behaviors, making excuses becomes more difficult. At this point, it's very important to get to a doctor and begin to prepare for safety.

In the **late stage** of dementia the patient has increasing difficulty concentrating. Additional changes could include a loss of awareness of surroundings, trouble communicating, and changes in personal hygiene requiring higher levels of care. Patients decline physically and become prone to infections.

Progressive changes require greater assistance in caregiving. It's clear that the patient should no longer live alone and requires regular support. Several options for increased care are outlined in this booklet. At this stage family members feel incredible turmoil within themselves and within the family. Difficult decisions will need to be made.

The future isn't predictable for any of us. Dementia does not follow one path. Eventual decline in memory is expected over time. The timing differs for everyone. Some medications may slow the progression of memory loss but, to date, nothing can stop it entirely.

5 *How do I care for my loved one?*

Patience, patience and more patience.

Adjust your own expectations. Memory care patients do not realize they are forgetting. Do not expect them to know they're "forgetting things". Do not argue with your loved one. They often are unable to modify their behaviors. Listening and redirecting are the best tools to use when interacting with a patient with dementia.

It is important to recognize the patient is living in a different reality and that it can cause them confusion, paranoia, and agitation. They may accuse you or others of "stealing" from them. When they don't recall where they've placed something they'll typically assume someone has taken it. Don't be embarrassed or ashamed by your loved one's condition. **Limit anything that can agitate their emotional state.**



Take care of yourself, too. **Reach out for support.** What seems so "abnormal" is actually quite normal in someone with dementia. It can be helpful to recognize that the decline requires you to adjust your manner in relating to your loved one.

Distract, distract, distract. Individuals with dementia often have poor focus which enables others to easily direct their attention away from a situation that may be causing distress or emotional escalation.

Be agreeable. There's no point to correcting someone with dementia on their misperceptions (i.e. as to the current year or where they are). They do not realize they are forgetting and your correction will be forgotten as well.

Spend time **talking about events they do recall** rather than those they do not. It is pointless to try to get someone to recall something they quite simply cannot. The memory is, for all intents and purposes, gone.

The more dementia progresses, the more that memory regresses. They will be thinking, and recalling, memories from younger and younger ages. Belaboring a fact or issue they cannot remember will only make your loved one feel they have done something wrong and they have no known reason why. This in turn may create anxiety, frustration and, even, anger in your loved one as they struggle to understand something they have no recollection of at all.

Embrace conversations of events and remembrances that occurred earlier in their life. **Reminisce** about what brings them joy, happiness, or calmness.

Speak slowly, in short phrases and with good eye contact. Redirect as necessary, without escalating your tone, even when you're frustrated.

Remove extraneous visual and auditory noises. Too much stimulation causes them to feel overwhelmed.

Play music and songs from their era. This helps them connect with you and create memories.

Use hand signals and facial expressions to convey meaning as language can deteriorate in later stages.

Gentle touch can convey warmth, However, it could also cause distress.

If your loved one is showing **signs of wandering**, seriously consideration of a memory care facility is necessary for their safety. The risks are high if they leave their home alone and become confused or disoriented. They could suffer exposure to the elements, dehydrate, fall, sustain an injury, or worse. You have to protect the patient from wandering.

Ask for help. Communicate openly with those in your support system. Be open about what you need. Seek respite care. Take breaks even when you don't think you can.

Practice **self-care** taking the time you need to stay healthy. If you become ill or depleted you cannot care for the patient who is now dependent upon you. You must remain strong and healthy.

Finally, make “**Informed Decisions**”. Gather information, research options, ask lots of questions, and contact professional organizations like Elderwerks. For additional help find an Elder Law Attorney.

6 *Can care continue at home?*

Yes, provided the caregiver is healthy. Ask yourself if you feel up to the task. Do you have support? Emotionally, can you take on the responsibility? Routine is important.

Do not do this all by yourself. It's necessary to build a community to help you. Be mindful about building in key factors to enable your own resilience. You'll need to be prepared.

Safety is the primary concern. Don't wait for the accident or incident, learn what to look for to avoid tragedy. You will need to make the home safe for your loved one. Ovens, locks, candles, lights, stairs, nighttime, throw rugs must all be considered to prevent injuries and accidents. Consult with others who have been through this experience. There are many things you may not consider a risk.



Some **considerations** when caring for your loved one at home: Are they easily agitated? Is there any risk of violence? Is alcohol a factor? Do you drink? Do they drink? Is your loved one at risk of wandering and potentially getting lost or exposed to the elements? Can you manage medications needed? Are you good at structure and routine?

Bringing **assistance** into the home is positive and sometimes necessary option. If family members can be alternates in assisting, this can take the pressure off of one person being the sole caregiver. There are numerous organizations that assist with bathing, medication, cooking, cleaning, socializing, finances, etc.

A good assessment will help you decide what best meets your needs.

7 *What are the options if my loved one cannot live at home?*

Reasons people consider a residential facility:

- Home safety
- Increased care needs of your loved one
- If the caregiver is gone a lot
- Wandering, leaving the home unattended
- To improve social stimulation
- Sundowning, aggressive behavior becoming pronounced later in the day

Contact an expert referral source like Elderwerks. They can provide you with information about appropriate facilities that best meet the needs of your loved one.

The **options for residential living** are:

- Independent Living
- Assisted Living
- Memory Care
- Supportive Living
- Skilled Nursing Facilities

Costs are covered by private pay, long term care insurance, Medicare, or assistance programs. Advisors are available through organizations such as Elderwerks.



Independent Living

Independent living facilities provide private apartments, meal options, opportunity for social engagement, and some house cleaning and laundry services. This option may be appropriate for those in the early stages of the illness, but each residence will provide their own assessment to determine this. Most often those with dementia are best suited for Assisted Living or Memory Care where they have the option of increasing levels of care as the illness progresses.

Assisted Living

Assisted living facilities provide a higher level of care. Assistance is available for medical needs, mobility assistance, and personal care. Assisted living facilities also provide meals, laundry, housecleaning, and onsite nursing around the clock. Social engagement is provided and encouraged.



Supportive Living

Supportive living environments are residences that accept Medicaid as a payment option.

Skilled Nursing

Skilled nursing facilities provide the highest level of medical and personal care for your loved one and are typically utilized once a patient is no longer ambulatory.

8 *How do I take care of myself while caring for my loved one?*

Take care of yourself first!

Your loved one needs you now more than ever. You can only be an effective caregiver if you take care of yourself. As stated previously, 'in an emergency, put on your oxygen mask first and then assist the person next to you. The person next to you is your loved one!

- Take time out to relax, read a book, watch a movie, garden, visit friends
- Experience the benefits of exercise. Simply walking, preferably in a nice setting, can soothe the mind & body
- Enjoy the confidence of a friend. It's okay to vent about your struggles & frustrations
- Play and plan activities that bring you joy
- Learn new things, explore new interests whether at home or somewhere else
- Take healthy escapes, mini breaks to a spa, massage, manicure, or overnight get away
- Write in a journal. Expressing feelings on paper is a powerful tool
- Maintain an attitude of gratitude. Look for the simple gifts of the moment, not what was lost but what you have
- Practice stress management, mindfulness & breathing techniques, yoga, proper eating, and sleep



Caregivers can experience any of these common problems:

- Symptoms of Depression
- Symptoms of Anxiety
- Increased sense of guilt, sadness, dread or worry
- Ambivalence about caregiving
- Sadness in witnessing the decline of a loved one
- Fatigue, low energy
- Sleep problems (too much or too little)
- Risk of illness, injury, mortality
- Trouble with keeping up

- Financial strains
- Relationship stress
- Loss of time for self-care
- Reduced quality of decisions
- Fears about the future
- End of life care planning
- Overwhelmed by finding resources and services
- Finding quality healthcare
- Finding community services
- Guilt about using respite care or taking breaks
- Family challenges
- Conflict about care
- Lack of support for caregiver
- Balancing needs of healthy and sick family members
- Angry or dependent behavior of loved one
- Increased irritability in other relationships
- Stress of advocating for loved one
- Lack of cooperation by loved one
- Challenges coordinating care

Recognize the signs of burnout:

- Denial
- Anger
- Isolation
- Anxiety
- Depression
- Exhaustion
- Difficulty sleeping
- Irritability
- Difficulty concentrating
- Health decline
- Running on adrenaline
- Running on empty



Try practicing these skills in an effort to avoid burnout:

- Come to a point of acceptance
- Utilize healthy coping skills
- Have the courage to be imperfect
- Remember it's okay to ask for help
- Take care of yourself physically, emotionally, mentally, and spiritually

Staying connected to yourself or consult with a professional from a supporting organization, therapist or self-help or support groups.

9 *How do I stay connected to my loved one?*

Engage in **activities** with them. Laugh together. Don't argue about their orientation to time or place. Go with what they give you. Stay in the moment with them. Long term memory for them is more intact so allow them to repeat their memories as many times as they choose. This is their way of engaging with you and sharing their life with you now.

Look for **"Incidental Gifts"**. Caring for another can enhance spiritual growth if one is paying attention. Taking care of your loved one also increases compassion, patience, and value in the simple things in life.

Lower your **expectations**. Your loved one is not the same as they used to be. The relationship has changed and expectations of the patient should be modified. Try to accept "what is" and let go of "what used to be".

Practice **patience**. They are not forgetting on purpose. They are suffering memory loss. Expect to repeat yourself, sometimes a lot. For routine things, leaving the patient notes can be helpful.

Prepare to **live in the moment** with your loved one. This is the concept of mindfulness.

Identify and **deal with your own feelings** about the challenges of coping with your loved one. It can be very hard on family members to deal with the changing roles (i.e. the child is now caregiving the parent). Allow for a full range of feelings from gratitude to frustration, loss, and profound sadness.



Appreciate the gifts. Look for the laughter, the spark in their eyes, or a caring touch. Join them where they are rather than enforcing your own agenda.

Understand the process, expect them to live in the past. The further the dementia progresses, the more they're likely to recall earlier times of life. As the disease progresses it's not uncommon for comfort objects to be a doll or stuffed animal.

Don't be limited by what you knew about them. Be prepared to be surprised. There may be new things to learn about your loved one. Embrace it all without judgment.

Suggested Activities with your loved one:

- Have discussions with them about family, history, vacations, work, hobbies
- Create a scrapbook or photo album and label the people and places they recall
- Create a timeline of their life or what they remember from their parents and family of origin
- Write down stories they share with you
- Reminisce about your favorite memories together
- Cook meals that have meaning from your life together, use their recipes
- Engage all the senses: touch, see, hear, smell, taste
- Create new memories for yourself with your loved one

10 *How can a Social Worker or Psychologist help?*

Having a Social Worker or Psychologist check in can assist in **ongoing assessment and monitoring** of symptoms. To your loved one it may just seem like a nice person coming to visit, however, the social worker is actively watching for symptoms of anxiety, depression, agitation, social engagement, increased confusion, memory loss, safety concerns, etc. For those living at home, the socialization of the visit alone can be a comfort and help to improve quality of life.

The clinician also **collaborates care** with medical professionals, residential staff, and family members. Concerns and questions are discussed with the Power of Attorney.

A Psychologist or Social Worker can be instrumental in **assisting the caregiver** with the multiple dynamics involved in caring for someone at home or in a facility. The coordination of care can be overwhelming. The clinician has numerous contacts and experiences that can contribute to assembling the right team for your circumstances and help in understanding what is happening to your loved one and yourself.

Caregiving is an emotional process and having a **professional confidant** can be a relief in a stressful situation. The feelings around the decline in a loved ones health is a painful journey that no one should walk alone. Having dealt with families, the clinician can help navigate this unfamiliar territory by providing **assessment and resources**.

As a caregiver, life has profoundly changed. Not only the reality, but the plans you had about what life was “supposed to be like” in your later years. **As a caregiver**, your own sessions with a psychologist or social worker can help you process the range of feelings that come with this experience. It’s a place of no judgment. You can express all that you’re thinking and feeling. You’re encouraged to take care of yourself and reminded that you matter, too.

While the Social Worker or Psychologist can intervene on multiple levels with presenting issues, they are sometimes limited by the progression of the disease. Bathing, agitation, noncompliance, and lack of insight are all evidence of the dementia and not necessarily “bad behaviors”. While these present as concerns to caregivers, accepting the decline and adjusting expectations may do more for your loved one than trying to combat the issue.

A Final Note:

Caregivers rarely regret their part in caring for a loved one. It’s a call that challenges on all levels. When it’s over, most people find they’ve learned very valuable life lessons. They may have found **purpose and meaning** in a new and different manner than what they’ve defined over time. They’ve **built their own memories** and discovered what truly connects us as human beings. They’ve **opened their own heart** to be vulnerable. Most find they’re **stronger** than they knew. While caregiving has its burdens, it also has its **blessings**. The gifts are often realized “after the fact”.

Some research has shown that **caregivers are heartier and live longer** than people who don’t take on caregiving roles. The Center on Aging and Health at Johns Hopkins University in Maryland states that research shows caregivers live an average of 18% longer than those who do not take on caregiving. The reason is caregivers learn how to master and overcome challenges. They learn they are more resilient than they ever imagined.

When a caregiver loses a loved one, it can leave an enormous void that requires a reexamination of life and identity. As caregiving began, life reorganized around taking care of the loved one. When their loved one is gone, the caregiver must find the resources and resilience to carry on with their life. Many will try to bring their new gifts to the world in a meaningful way. In the end, they know that they have the strength to get through almost anything.

Resources:

-Alzheimer's Association
www.alz.org/

-Alzheimer's Association Community Resource Finder
www.communityresourcefinder.org/

-Alzheimer's Foundation of America
www.alzfdn.org/

-Elderwerks Educational Services
www.elderwerks.com

-Family Caregiver Alliance
www.caregiver.org/

-Health In Aging
www.healthinaging.org/

-HelpGuide.org
<https://www.helpguide.org/articles/caregiving/support-for-alzheimers-and-dementia-caregivers.htm>

-National Adult Day Services Association
www.nadsa.org/

-National Institute on Aging
www.nia.nih.gov/alzheimers/relieving-stress-anxiety-resources-alzheimers-caregivers



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It has been our greatest blessing to come to know the families and patients that have traveled this road. Most of our Psychologists and Social Workers know from personal experience the role of caregiving.

Out of these experiences, we've chosen to combine our education and life experience to care for and support those that are facing similar issues. We laugh with you, we hurt with you, but our ultimate wish is to help lighten your load and bring comfort.

For that we thank you.

Services are covered by Medicare and can be courtesy billed to your secondary insurance as well.

We Want to Hear From You



Little Lexi Lu and Miss Myla Mae

Certified Canine Good Citizens and Certified Therapy Dogs

You may see us out & about with Little Lexi Lu and Miss Myla Mae (on *your* left and right respectively) as we visit homes and facilities with our staff.

Studies have shown that this interaction proves beneficial to all ages and can help the dementia patient to connect in a manner that requires no words. If you have a request to visit with the dogs, please, let us know.



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