

■ ■ CONSIDER THIS:



A guide for patients and families
experiencing neurocognitive impairment,
memory loss, and/or dementia



Consider This: A guide for patients and families experiencing cognitive impairment, memory loss, and/or dementia

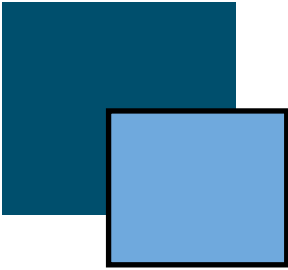
Coproducers:	Debra Thaler Gilroy, Ph.D., Northshore Psychological Associates, LLC Thomas Skelly, CRNP, UPMC Northshore Neurology
Author/Designer:	Debra Thaler Gilroy, Ph.D.
Primary Contributors:	Nykole Gonzalez-Mestres, Psy.D. Thomas Skelly, CRNP
Additional Contributors:	Ruby Glass, Student Intern Tammy Kordes, Ph.D. Rebecca Parkhurst, PA-C Brenda Vargo, M.S.
Second Edition:	August, 2026

Publishing of this guide is made possible through a contribution from the
Albert A. Dematteis Memorial Neuro Education & Technology Fund
Hamot Health Foundation.



This document has been prepared as a collaboration of neurology and neuropsychology professionals at Northshore Psychological Associates, LLC, and UPMC-Hamot Neurology, both located in Erie, PA. If you have questions or comments regarding this document, please e-mail dgilroy@nspractices.com or ngonzalez@nspractices.com

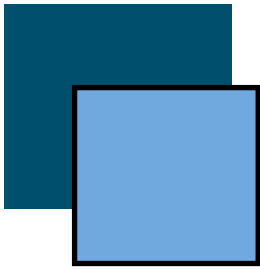
© **Copyright 2023/2026 @ Debra Thaler Gilroy, Ph.D.** All rights reserved. No part of this publication may be reproduced or transmitted in any form without prior written permission, except for brief quotations in reviews.



CONSIDER THIS:

Table of Contents

Introduction.....	3
What I Would Want My Loved Ones to Remember.....	5
Understanding Cognitive Impairment.....	6
Activity: Why It Matters.....	8
All About Behaviors	9
Ambulation & Falls.....	12
Caregiver, Care Partner, Care Manager.....	13
Communication: Making It Count.....	14
Community Services.....	17
Disease Stages & Course.....	18
Driving Decisions.....	19
Health Care Management.....	21
Home Care: When, Who, & How Much?.....	22
Hygiene: How To Help.....	24
Legal Issues: Plan Ahead.....	25
Living Arrangements.....	26
Meals, Nutrition & Healthy Choices.....	27
Medication Management.....	28
Mental Health Of Patients & Caregivers.....	31
Memory & Cognition: Compensatory Strategies.....	32
Routine & Disruption.....	33
Safety & Supervision.....	34
Scams & Fraud Risks.....	36
Sleep & Sundowning.....	37
Travel Tips.....	38
Wandering & Disorientation.....	39
Resources.....	41



CONSIDER THIS: Introduction

If you or a loved one is diagnosed with cognitive impairment, memory loss, and/or dementia, you may have many questions and concerns. This initial guide has been prepared to give an overview of considerations, along with some resources you might find helpful now and in the future. *This guide is not an exhaustive list of information or resources*, but is presented as a starting place for caregivers and loved ones. Additionally, more detailed internet, local and national resources, and informational links can be found at the end of this document in the *Resources* section. Your neurologist, neuropsychologist, family doctor, mental health practitioner, physical therapist, occupational therapist, and speech/language therapist are good sources of information as well.

There are several myths about memory loss and dementia, including that people experiencing cognitive impairment can't understand what is going on around them. This belief results in the impacted individual being subjected to "unjust and unfounded assumptions about their abilities."¹ Hopefully, the information in this document will help patients and families better understand the dementia spectrum as it relates to their own experiences.

The *Consider This* guide format uses a brief description of specific areas of concern, an extra tip for each issue, and a list of *Resources* that includes specific websites, books, and services available.

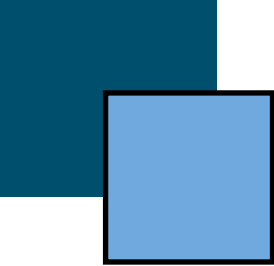
Not all information you read here will apply to every case or individual, as every case is different in some ways. This document, however, can assist in understanding and managing various aspects and behaviors found to be associated with varying levels of cognitive impairment.

¹*Myths and Realities of Dementia*, Alzheimer's Society of Canada, <https://alzheimer.ca/en/about-dementia/stigma-against-dementia/myths-realities-dementia>

“You are more than what you can remember.”

*Lisa Genova, from **Remember: The Science of Memory and the Art of Forgetting**²*

²*Remember: The Science of Memory and The Art of Forgetting*, Lisa Genova, Harmony Books, copyright 2021

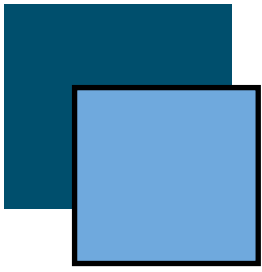


What I Would Want my Loved Ones to Remember If I Had Dementia³

- ♦ I want my friends and family to embrace my changing reality. If I think my spouse is still alive, or if I think we're visiting my parents for dinner, let me believe those things. I'll be much happier for it.
- ♦ Don't argue with me about what is true for me versus what is true for you.
- ♦ If I am not sure who you are do not take it personally. My timeline is confusing for me.
- ♦ If I am sad or anxious, hold my hand and listen. Don't tell me my feelings are unfounded.
- ♦ Don't treat me like a child; talk to me like the adult I am.
- ♦ I still want to enjoy the things that I've always enjoyed. Help me find a way to exercise, read, and visit with friends.
- ♦ Ask me to tell you a story from my past.
- ♦ If I become agitated, take the time to figure out what is bothering me.
- ♦ Treat me the way you would want to be treated.
- ♦ Don't talk about me as if I am not in the room.
- ♦ Don't feel guilty if you cannot care for me 24/7. It's not your fault and you have done your best. Find someone who can help you or choose a great new place for me to live.
- ♦ If I live in a dementia care community, please visit me often.
- ♦ Don't get frustrated if I mix up names, events or places. Take a deep breath and understand it's just that my brain is working quite right.
- ♦ Make sure I always have my favorite music playing within earshot.
- ♦ If I like to pick up items and carry them around, help me return those items to their original places.
- ♦ Don't exclude me from parties and family gatherings, but help me avoid overload.
- ♦ Know I still like receiving hugs or handshakes.

♦ *Remember I am still the person you know and love.*

³Adapted with permission from Rachael Wonderlin, www.rachaelwonderlin.com. Rachael Wonderlin is a dementia consultant and author best known for her *Embrace Their Reality*TM approach and *Dementia by Day*TM training programs.



CONSIDER THIS: Understanding Cognitive Impairment

Mild Cognitive Impairment: As defined by the Mayo Clinic, “*Mild Cognitive Impairment (MCI)* is the stage between the expected cognitive decline of normal aging and the more serious decline of dementia. It's characterized by problems with memory, language, thinking or judgment.

If you have mild cognitive impairment, you may be aware that your memory or mental function has ‘slipped.’ Your family and close friends also may notice a change, but these changes aren't severe enough to significantly interfere with your daily life and usual activities.

Mild cognitive impairment may increase your risk of later developing dementia caused by Alzheimer's disease or other neurological conditions. But the majority of people with mild cognitive impairment never get worse, and a few eventually get better.”

Major Neurocognitive Impairment: As defined by the Mayo Clinic, *Major Neurocognitive Disorder (dementia)*: “Dementia is a term used to describe a group of symptoms affecting memory, thinking and social abilities severely enough to interfere with your daily life. It isn't a specific disease, but several diseases can cause dementia.

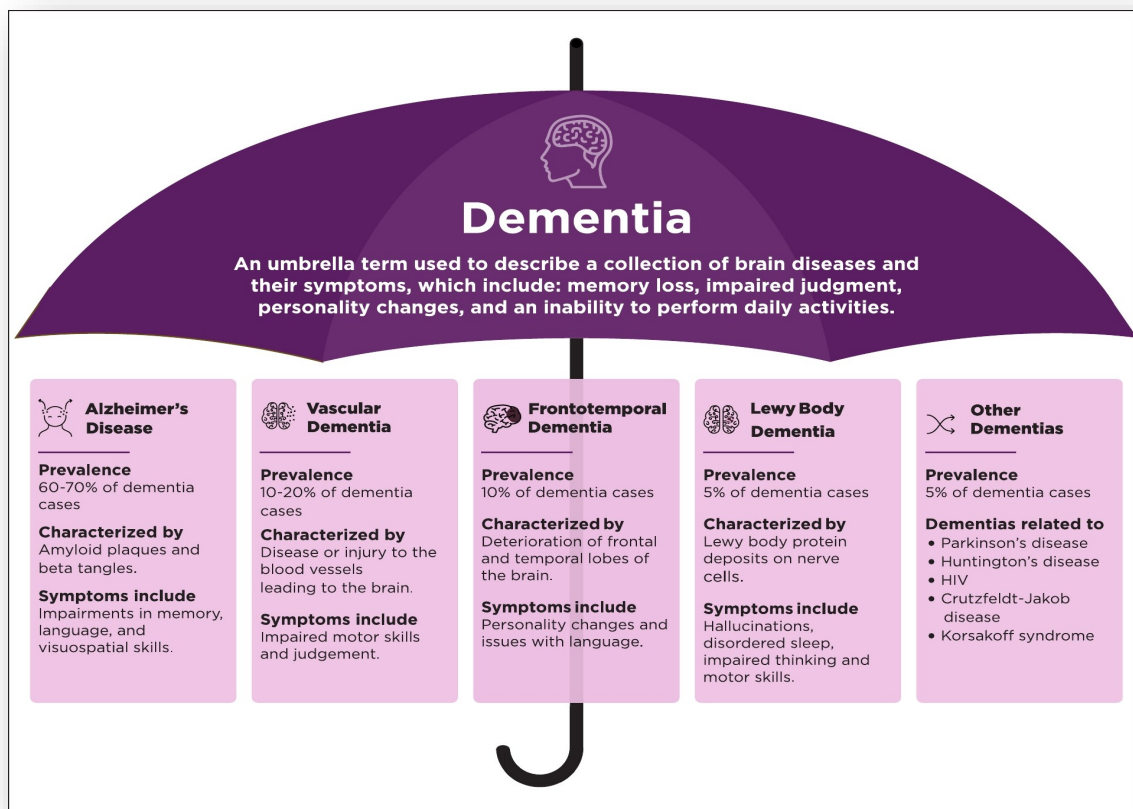
Though dementia generally involves memory loss, memory loss has different causes. Having memory loss alone doesn't mean you have dementia, although it's often one of the early signs of the condition.

Alzheimer's disease is the most common cause of a progressive dementia in older adults, but there are a number of other causes of dementia. Depending on the cause, some dementia symptoms might be reversible.”

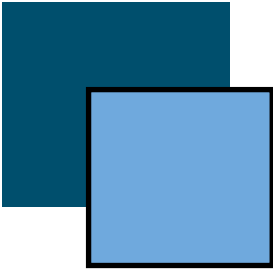
The Dementia Umbrella: Another way to look at neurodegenerative diseases, such as dementia, is to understand it is a process of brain cell compromise. Since not all brain cells regenerate as, for example, skin cells do, the brain must find different ways and paths to function, communicate, and compensate for losses. Since the brain controls thoughts, emotions, behavior, and bodily functions/movement, deficits can occur for the impaired individual in any of these areas, resulting in changing and shifting presentations.

Understanding Neurocognitive Impairment

There are several types of dementias. Think of dementia as the tip of an umbrella, with each umbrella spoke representing a different type of disease. More information on the various types of dementias including symptoms, contributors, course, and treatment is found in the [Resources](#) section. Be aware that many of these types of dementias are not diagnosable with imaging or blood tests, but instead medical professionals use experience, functional neuropsychological testing, and differing physical and cognitive patterns for diagnostic purposes. There are several other types of dementia aside from those on the chart below, but these are the most prominent.



Many people with a dementia diagnosis live long and productive lives. When a patient or family member/friend hears the word 'dementia', for example, they may envision the worst possible scenario. But dementia severity is on a spectrum, and many factors contribute to the functionality and stability of the individual, including cognitive resources. It is critical for patient and caregivers alike to recognize that individuals with major cognitive impairment or dementia, like individuals with diabetes or heart disease, can and want to continue living as full and productive of a life as possible.



CONSIDER THIS:

Activity: Why it Matters

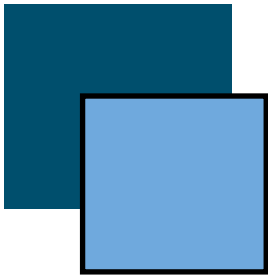
Research has consistently demonstrated that multiple levels of activity are important for brain health and can assist in maintaining levels of functioning longer. These interacting factors include:

- **Physical activity**, as tolerated and approved by your health care team, is an important factor to maintain overall health and wellness. Yoga, chair yoga/exercises, walking, and other forms of safe physical movement are recommended. Walking 20 minutes four days per week has been associated with slowing the rate of memory loss.
- **Interactive cognitive activity** is essential for keeping brain cells working. Television is not generally considered an interactive activity, although programs that elicit a response such as Jeopardy and Wheel of Fortune can be helpful. Jigsaw, word and crossword puzzles, playing cards, reading, creating art, discussions, continuing to be productive in some way, and similar activities, at levels tailored to needs, interests, and capabilities, are best.
- **Socialization** is another activity that is important to consider. Interaction with family members, friends, and others can lift spirits and provide caring support for the impacted individual in addition to contributing to a healthier brain.

The ability of the impacted individual to perform any of these activities will vary over time and sometimes even from day to day. It will be important to assess these abilities regularly and to encourage, and provide opportunities, suggestions, and coaching regarding patient involvement. It is also important, however, to avoid pushing to the point of aggravating the impaired individual.

Finding activities can be difficult, but gatherings such as The Memory Café, outings sponsored by organizations, including North Shore Psychological Associates, can offer opportunities for socialization. For more information on these and other activity ideas, see the [Resources](#) section.

Extra Tip: *For more advanced dementia individuals, especially those who become restless and try to move household items from one place to a not-so-appropriate place in the home, one try creating a fidget kit that includes safe small household items, old board game pieces, picture books, small toys, and other items caregivers know the dementia patient might like – this helps with both restlessness and cognitive activity.*



CONSIDER THIS: All About Behaviors

In some cases, agitation and/or behavioral issues can develop during the course of neurocognitive impairment. A list provided by the WAIDDC⁴ highlights the following issues:

- ☐ Forgetfulness and confusion
- ☐ Repetitive speech and actions
- ☐ Mood swings
- ☐ Personality changes
- ☐ Diminished initiation
- ☐ Depression/anxiety symptoms
- ☐ Inability to plan/structure time and activity
- ☐ Sleep/wake cycle disturbance
- ☐ Suspiciousness and paranoia
- ☐ Agitation and aggression
- ☐ Sundowning behavior
- ☐ Delusions and hallucinations
- ☐ Shadowing and clinging behavior
- ☐ Restlessness, pacing, wandering

Some, but not all, individuals will develop acting out or behavioral disturbances that feel unmanageable and overwhelming to caregivers. Many caregivers find this type of behavior increases at the end of a day, often referred to as ‘sundowning’. Often, agitation or behavioral issues develop when the impaired individual is not able to effectively communicate their needs, wants, or physical discomfort. This means that caregivers must become ‘detectives’ to identify the problem the impacted individual cannot verbally communicate or may not even be fully aware of. Arguing or confronting is not going to work and is likely to escalate the situation. Distraction, redirection, compassion, and understanding are better choices.

When there are accompanying psychological issues, agitation and acting out behaviors are more likely. It is critical that caregivers understand these behaviors are the result of the disease impacting brain cells and to avoid taking the impaired individual’s words or behaviors personally. Addressing these issues begins with

⁴Wisconsin Alzheimer’s Institute Dementia Diagnostic Clinic, from a flyer produced by Jody Krainer, MSW, LCSW, MBA, *Complex Behaviors with Alzheimer’s Disease*

caregiver reflection, asking the question ‘Is the behavior problematic, and if so, to whom?’ and ‘What has worked regarding this behavior in the past?’ For example, if an impaired individual is continually pacing back and forth, as long as they are in a safe environment and they are not at risk of falls, perhaps recognizing the behavior as a release of energy is the prudent choice. There are several ways for a caregiver to help the impaired individual depending on the frequency and intensity of the behaviors. These include, but are not limited to:

- ☐ A calming environment established via sensory stimulation such as peaceful music and a calm, non-confrontational, non-threatening approach
- ☐ Simple, direct and short sentence communication including redirection to shift focus
- ☐ Addressing hunger, thirst, and nutrition
- ☐ Providing reassurance without arguing, as the impaired individual is not likely to respond to being told they are wrong since their reality may be different due to their disease
- ☐ Emphasize and acknowledge the concerns presented by the impaired individual regardless of their logical validity
- ☐ Avoid using command statements or ‘bossy’ directions; suggestions, choices and gentle persuasion are more effective
- ☐ Maintain routines as much as possible to avoid creating anxious and agitated responses to perceived discomforting changes
- ☐ Provide an open, safe, and contained environment
- ☐ Strike a balance between deprivation of sensory experiences and over stimulation
- ☐ Provide adequate eyesight and hearing aids, as the impaired individual may not be able to communicate their needs
- ☐ If it is necessary for the patient to be out of their routine and normal environment, such as in a family gathering, have them sit in a quiet room and let family members visit one or two at a time so as not to overwhelm
- ☐ Lighting is important, and having night lights may help an impaired individual be less confused if they wake in the night
- ☐ For those impacted individuals who may become aggressive, always place yourself in their line of vision so they can see you
- ☐ Also, ask for permission prior to engaging in an activity such as assisting in a change of clothes and couple this with telling the individual what you are doing as you are doing it. For example, “I am buttoning your shirt now,” as this avoids startling them or catching them off guard and is respectful of personal space

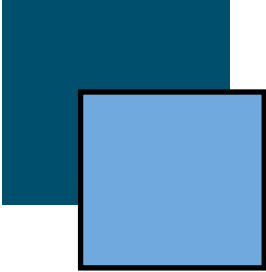
More detailed information on behavioral management is provided by several specialists in the dementia field. Several options are listed in the *Resources* section of this document.

When someone has dementia you just have to inhabit their parallel universe with them. There is nothing to be gained from challenging their take on reality.

Angela Rippon

***A Note on Sundowning....** According to the Mayo Clinic, the term ‘sundowning’ refers to a state of confusion recurring in the late afternoon and lasting into the night. Sundowning can cause different behaviors, such as confusion, anxiety, aggression or ignoring directions.” For more on this syndrome, see the separate section in this document.*

***Extra Tip:** Occasionally, in some cases of agitation and behavioral dysfunction, the caregiver may themselves feel at risk, or observe that the impaired individual is in danger or out of control. In these cases, use emergency services such as 911, call your local mental health CRISIS Line (in Erie area 814-456-2014) for assistance, or proceed to an emergency room. Be sure to have a list of medications and medical conditions to give responders and to explain the individual experiences dementia symptoms and has been diagnosed with neurocognitive impairment.*



CONSIDER THIS:

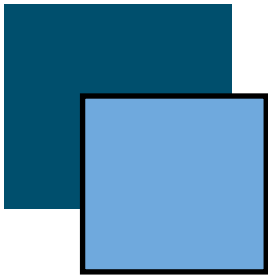
Ambulation and Falls

Whether the impacted individual is living alone or with others, as impairment progresses, and depending on other contributing medical conditions, walking and balance may become more challenging over time. Some individuals are aware of their limitations in this regard, but many are not. Alternatively, your loved one may not be willing to use an assistance device such as a cane or walker because of the stigma they feel or due to denial/lack of insight regarding their own abilities. Or, they might simply forget to use a cane or walker, even when it is placed in front of them. Regardless of the reason, fall risk is an area to monitor regularly.

There are several ways to encourage and ensure your loved one uses appropriate devices regularly, ranging from chairs designed to help the person stand more easily, gentle encouragement and reminders, behavioral incentives, and establishing routine. That being said, it is impossible, unless someone is with the individual every minute of every day and night, to guarantee no falls. Once a caregiver has limited the fall risk to their best ability, the next step is inclusion of a device that can alert you and safety personnel if a fall risk is imminent or a fall occurs.

For example, many dementia care facilities use chair alarms to alert caregivers the impaired individual has left or is leaving their seat. More common for individuals who reside in a family home or their own home is an alert system to call for help. There are many of these on the market. Information on this and other services is provided in the [Resources](#) section of this document, along with links regarding fall prevention tips. Additionally, if ambulation is independent but slow or puts the individual at risk for falls, consider asking your health care professional to request a handicapped placard from the state department of transportation.

Extra Tip: *Not all cognitively impaired individuals have balance or fall issues. However, if the individual has existing or developing medical conditions and/or physical disability, personal monitoring and/or device monitoring is essential and it is important to reassess risk regularly.*



CONSIDER THIS:

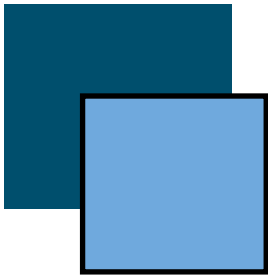
Caregiver, Care Partner, Care Manager?

Caregiving for family members or friends with dementia or neurocognitive impairment can be a part or full time job depending on the stage of impairment and whether or not the impacted individual is living at home. Caregiving can be both extremely rewarding and equally challenging. There are good days and bad days, and there are days when it seems the impaired individual remains your loved one as he or she used to be. But it can drain caregiver energy and become more difficult as the impacted individual declines in cognitive function. It is important that the caregiver(s) take care of themselves as well as caring for the impaired individual. This includes time off, activities that fill the caregiver energy tank, and monitoring their own health, both mental and physical. Studies consistently show caregiver “burnout” can be avoided with good self care and a clear understanding of their own limitations.

Often, caregivers are so involved with providing the needed care for the impaired individual that they may ignore their own health needs and health care services. There are a number of ways to care for the caregiver, including arranging a schedule for others to provide respite regularly, whether they be family members, friends, or hired aides. Support groups for families of dementia patients are also a good resource, and some are available online, to make it easier to attend. Individual supportive counseling may also be an option.

For patients AND caregivers, the shift in needs can contribute to a shift in the relationship. It can be helpful to break down the caregiving responsibilities into the categories of care manager, care partner, and caregiver. The *care manager* handles appointments, planning, support services, and health care coordination. The *caregiver* is responsible for the day-to-day hands-on responsibilities of providing food, hygiene, routines, and activities. The *care partner* is responsible for meaningful communication, relationship, empathy, and adjustment to the changing roles. In creating these categories, it may be easier for the individual responsible for providing care to share or divide some of the responsibility with individual family members, friends, or paid home care specialists, while taking care of themselves and the impaired individual.

Extra Tip: Check the *Resources* section of this document for support group resources and caregiver information, including on-line groups. Additionally, caregivers may need the support of a mental health counselor for themselves as they navigate the sometimes difficult and emotional landscape of caring for a dementia patient. Options are listed for these services as well.



CONSIDER THIS: **Communication: Making it Count**

One of several early signs of cognitive impairment can be the way the impaired individual communicates. Over time, an observer may notice more than usual word finding difficulties, word substitution, question and story repetition, verbal outbursts, mixed phrases, and losing train of thought. These issues can contribute to frustration for both the impacted individual and the caregiver, and can also increase/change as disease progresses. The Mayo Clinic has listed several strategies relevant to communication with a person who has neurocognitive impairment. Some of these include:

Patience: Plan enough time and listen to the impacted individual without interruption, giving them time to complete verbalization. Remember that when the individual asks the same question repeatedly in a short period, it is usually not because they did not hear or even understand your response. It may be because the individual forgot having asked the question and having received your response or because they may need continued reassurance.

Interpretation: Place the communication in context of the current moment. If the individual cannot get a whole thought across, try to suggest, or guess what is being communicated. Caregivers can use cues, prompts, and mirroring techniques. Caregivers can offer comfort to the impacted individual when they are struggling to speak coherently.

Nonverbal Communication: Be at the same physical level as the impacted individual when they speak, hold eye contact, and perhaps hold hands if appropriate. Make sure caregiver body language is calm, relaxed, and unhurried.

Respect: Caregivers sometimes tend to use ‘baby talk’ or high voices to communicate with individuals with dementia. Try to avoid this tendency and to avoid phrases like “good girl”. Don’t talk about the person as if they are not in the room. Avoid saying “I already told you that” or “don’t you remember?”

Environment: Communicate in a calm, distraction free environment without television, chatter, or other stimulation that can interfere with attention and concentration.

Reality Check: An individual experiencing dementia also experiences confusion about what is going on around them and about timelines. This means they may at any given time be living a different reality than the caregiver. When possible, the caregiver should attempt to enter the patient's reality. For example, if the impaired individual is talking about a job they held decades ago like they are still working, ask them to tell you about their job, but don't deny or correct them.

Simplicity: As the disease progresses, one step at a time directions or requests and short sentences, can be effective. If there is resistance to a request, try offering choices rather than commands. Avoid yes or no questions, and offer alternatives. Additionally, avoid overusing the word "don't".

Correcting/Arguing: The impacted individual may not recall all the facts of a situation or story from the past and may arbitrarily fill in the gaps. It is critical not to correct them, as this is part of the disease process, and it is likely they may not recall the correction anyway. Avoid arguing about these issues as it only makes the situation worse for caregiver and impacted individual.

Visual Communication: Sometimes, especially as language and memory become more impaired, simply using a visual cue is better for understanding. For example, point to a drinking glass and water tap to see if the person is thirsty.

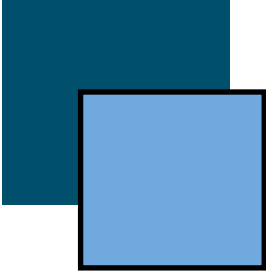
Stay in the Moment: When an individual with memory loss or cognitive impairment begins talking about something the caregiver does not understand or as if they are in a different time in the past, the impaired individual is on a journey the mind has created in its impaired state. Go there with them, visit for a while, and gently bring them back to today when it is necessary, for example, to use the toilet or eat a meal.

There are a number of brief online videos that give tips on communication and behaviors and how to best deal with them. Be careful to ensure that the source of your information is knowledgeable. Some of these individuals that appear to have appropriate advice and ideas are highlighted in the ***Resources*** section.

***A Note on Anosognosia...** Perhaps one of the major challenges for those experiencing cognitive impairment is the possibility that they do not know they are challenged, a condition called anosognosia or lack of knowledge of disease impact. Some individuals with cognitive impairment understand their limitations and are self-aware enough to know that it is time to give up driving, for example. With dementia, this self-awareness waxes and wanes over time, and in some types of impairment, is not present from the first diagnosis. It is not uncommon for individuals experiencing dementia symptoms to perceive no problems in one domain, such as driving, even when confronted with facts; yet they might recognize their memory challenges at the same time. One type of intelligence is intra-personal, that is, knowing the self, including strengths and weaknesses. And, like other brain cells and pathways, this intelligence can be compromised in a dementia process.*

Arguing with an impaired individual or expecting them to understand, for example, that it is unsafe to drive or use the stovetop, may be beyond their abilities to believe due to dementia related changes in the brain. Knowing that the impacted individual is truly not aware of all or some of the limitations caused by their condition can help caregivers to strategize, refrain from arguing, maintain empathy, and understand and find alternative ways to communicate.

***Extra Tip:** Sometimes, it can help for the caregiver to take a timeout when frustrated in communicating with an impaired individual. This can give perspective and a chance to calm frayed nerves. It can be incredibly frustrating to repeat the same information over and over in response to questions such as “when is my appointment?” In some cases, caregivers can write the basic information on a calendar or note card and present it to the impacted individual as opposed to verbally repeating.*



CONSIDER THIS: Community Services

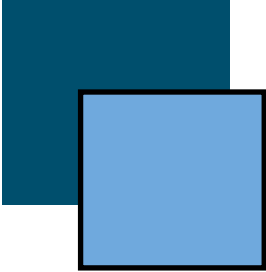
There are multiple community supports that you may access, depending on your needs. These needs vary over time for the impaired individual and include, but are not limited to, meals and nutrition, medication planning, in home supervision, life alert systems, cognitive training, social events, and so on. Access to these services in part is dictated by ability to afford them, but depending on income, there are public service organizations that can provide help.

Additionally, it may be helpful for patient or caregiver to provide documentation of diagnosis to local EMS, police and fire departments, as well as to use at airports if traveling with an impaired individual.

The Independent Council on Aging in Erie PA publishes a “Guide to Services” for Erie County specifically for older adults and their families, including topics such as emergency services, health care services, financial help, special needs, senior apartments, dementia, legal help, elder care, help with food, and so on. You can go to the website listed in the [Resources](#) section and download this guide or you can request physical copies at ICAeriePA@gmail.com

Extra Tip: Explore and become connected with the support services available early in the cognitive impairment process, as many have paperwork and lengthy processes before services can be provided. It is better for caregivers and patients to become familiar with these services to make it easier when and if services are needed.

The disease might hide the person underneath, but there’s still a person in there who needs your love and attention.” *Jamie Calandriello*



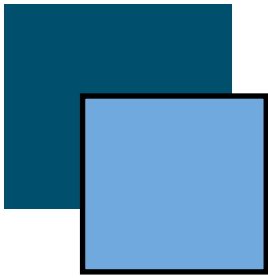
CONSIDER THIS: Disease Stages & Course

Many caregivers, family members, and friends express their concerns regarding the course of neurocognitive impairment diseases for the patient, wondering what to expect and requesting timelines. This is a very difficult question for most health care providers as the course of disease is different based on cause of impairment, stage of impairment, the impaired individual's physical and mental health history and status, cognitive and brain resources, and time of first diagnosis. There are many sources of statistics that give average stages and life spans, but again, these are averages only and are not an accurate predictor for every case. Some of this information is found in the [Resources](#) section via web links.

EARLY	MIDDLE	LATE
Symptoms: • Mild changes in memory and thinking • Some difficulties with daily tasks	Symptoms: • Moderate changes in memory and thinking • May have behavioral changes (hostility, agitation, anger, paranoia, hallucinations)	Symptoms: • Severe changes in memory and thinking • May have behavioral changes • Need help with most or all daily tasks
Concerns: • Plan now for future changes	Concerns: • Can often no longer live alone	Concerns: • Needs full time support
Actions: • Evaluate risks at home – these can be things like car keys, guns, or other household appliances • Plan for future changes at home	Actions: • Limit unsupervised access to firearms and driving • Supervise when at home	Actions: • Ensure no access to firearms and driving • Requires full time supervision

What seems more important is the quality of daily life for the impaired individual and family members. Much like the experience of the cognitively impaired individual, choosing to live in the moment and value communication and connection can be invaluable. ‘New normals’ occur over the course of dementia as cognition changes. These can last for extended periods, called plateaus, or short periods, as the brain is forced to continually adjust to brain cell loss.

Extra Tip: Be mindful of abrupt changes or decline in behavior or cognition, as these may not be related to cognitive impairment but possibly to other medical conditions such as a urinary tract infection or medication change. These types of rapid or abrupt changes may be reversible, depending on their cause, so bring them up to your health care provider immediately.



CONSIDER THIS: Driving Decisions

In our culture, driving a vehicle has come to represent independence and freedom. When an impaired individual is no longer able to do so safely, ceasing driving can become a significant contributor to depression, anger, and conflict with caregivers.

Please be aware that health care providers are required by law in the State of Pennsylvania to report to PennDOT if they have a legitimate concern about the individual's driving based on medical or psychological issues, and/or cognitive impairment. Additionally, in the state of PA, any individual (including family members) can anonymously report to PennDOT. PennDOT has published an excellent guide regarding senior driving safety tips and the process of reporting an unsafe driver, and the link for this guide is included in the [Resources](#) section of this document. A healthcare provider or family member report does not always mean a license is necessarily or automatically rescinded but may lead to the necessity for further evaluation and/or training.

Some impaired individuals will give up their license or driving voluntarily because they are fearful of their driving experience or because they recognize limitations. However, for individuals with significant cognitive impairment, there can be lack of recognition of unsafe driving practices and limitations. Additionally, they can lose orientation and/or become lost, causing increased safety issues. Caregivers, as much as they want to help maintain the impaired individual's driving privileges, will need to monitor this by accompanying the individual as a passenger to determine risks, arranging a driving test, or listening to others who are aware of the driving problems.

According to a recent flyer issued by the Transportation Solutions⁵ organization, warning signs regarding possible driving deficits include

- ☐ Inability to route plan or drive in unfamiliar areas
- ☐ Getting lost or confused with inability to reorient

⁵Transportation Solutions, 4202 Peach Street, Erie PA 814-833-2301., www.drivingneeds.com

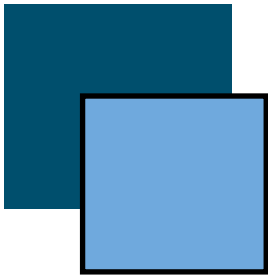
- ☐ Repeatedly forgetting where the car is parked
- ☐ Difficulty judging traffic
- ☐ Difficulty making driving decisions quickly and safely
- ☐ Other drivers honking at driver
- ☐ Stopping at a green light or at intersections without stop signs
- ☐ Fender benders, accidents, near misses
- ☐ Visuospatial deficits such difficulties in judging distance

If you suspect a possible problem, or want to determine if there is a driving challenge for the individual, there are some options including driving refresher courses and on the road driving evaluations listed in the [*Resources*](#) section.

Talking to your loved one who has dementia about driving is challenging. They may tend to overestimate their abilities, or shrug off fender benders as someone else's fault. They may often remind caregivers and health care providers "I have never had an accident" or "I've been driving for fifty years." Sometimes they become over cautious and drive drastically slower than the speed limit, which is also dangerous.

Try approaching the impaired individual from the angle of safety for self and others. The impaired individual may agree to get a driving test by experts. If necessary, the caregiver may have to involve a health care provider in this process.

Extra Tip: *If the impaired individual will need to cease driving, develop ways and lists on how they will now get where they want and need to go. Losing driving privileges contributes to the lack of control already being experienced by dementia patients, and providing options and mobility will make losing a driver's license more palatable. Family members, hired caregivers, and various paid transportation services can be a part of this plan.*



CONSIDER THIS: Health Care Management

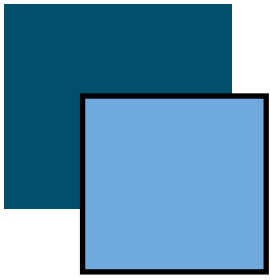
It takes a team of health care providers to help manage cognitive and medical needs, and each of them wants to be kept informed regarding activities and medication addition/changes. This can ensure continuity of treatment. It helps to make one caregiver responsible for health care management for the impaired individual, and this may be the person who is already taking care of organizing medications, or another member of the caregiving team.

Keep a list of health care providers and current medications for presentation at EVERY health care visit/appointment. Doctors, physician's assistants, nurses, therapists, and other providers will appreciate it and it helps to keep everyone on the same page regarding the treatment plan and medications. A list will come in handy when making appointments and managing medications as well.

In cases of dementia, the impaired individual will experience continued changes in cognitive function and likely physical health. Sometimes these changes are subtle, and other times abrupt; sometimes many aspects of cognition are impacted, and other times only a few. It is critical that these changes, when observed by caregivers, be noted and brought to the attention of the associated health care provider. For example, a person who, despite some memory decline, has been able to easily follow a recipe to bake an item starts to become confused or have difficulty engaging in this activity. Additionally, for those experiencing more advanced cognitive impairment, new health or medical issues may arise, but the impacted individual is unable to communicate or recall what is hurting or not working correctly. Caregivers can make a difference by observing. In another example, an individual begins to rub his knee repeatedly but does not comment on pain or even denies pain. In yet another case, an individual may begin picking at minor skin wounds and seem unable to stop doing so. Bring these issues to the attention of health care providers.

Additionally, it is critical to keep up with routine medical services such as flu, COVID, and pneumonia vaccines, regular physical exams, and seeing specialists as needed, all of which should be discussed with the patient's primary care physician.

Extra Tip: A good way to ensure coordination of providers is by accessing a portal such as mychart.com and/or myupmc.com, depending on which health care network the impaired individual participates in. These portals provide access to scheduled appointments, test results, medications, and messaging functions for setting up new appointments or asking questions.



CONSIDER THIS:

Home Care: When, Who, and How Much?

When and if an individual requires home care in addition to family caregivers is a difficult decision for most families and patients, as it is sometimes difficult to imagine a service provider, often a stranger at first, in the home. However, this may be a good option for those who want and are able to remain in their homes with appropriate help, and it is critical the primary caregiver has time for themselves.

- Several private agencies provide in home care at varying levels, including help with housekeeping, preparing simple meals, doing laundry, and providing socialization.
- Creating a team of family members and friends who are willing to help can often be used as an alternative to a hiring a service provider.
- Another good source for help can often be your church congregation; if relevant to your situation, seek out your pastor, reverend, or church leader to determine if there is a trustworthy congregation member (s) who is seeking to provide services for an appropriate fee.
- In Pennsylvania, a family member can get paid to be a caregiver through state and federally funded programs. Within programs like CDPAP (Consumer Directed Personal Assistance Program), care givers receive a paycheck for their hours worked, but be aware there are some eligibility limitations. The website for CDPAP is listed in the [Resources](#) section.

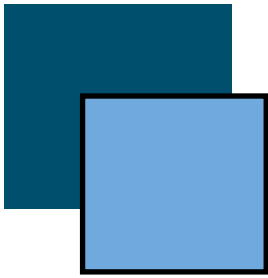
Whether working with a private agency or finding help through word of mouth, be sure to interview the outside caregiver to determine if they are the right fit for the impacted individual's home and needs; try to include the impaired individual in the conversation. Additionally, it helps to make a list ahead of time of what type of services you are looking for.

Another option many caregivers find helpful is day care services for seniors or dementia patients. These programs provide socialization, skilled supervision, and activities on half or full day schedules

***A Note on Types of Home Care...**There are several types of home care, as listed by The Alzheimer's Association, including:*

- ***Companion Services:** This involves supervision , engagement in activities, perhaps transportation for errands, and conversation.*
 - ***Personal Care Services:** This type of service assists the impaired individual with hygiene activities like bathing, along with help with dressing, eating, and toileting.*
 - ***Home Care Services:** This kind of homemaker services involves help with housekeeping, shopping, or preparing meals.*
 - ***Skilled Care Services:** These are medical services such as administering injections, taking care of wounds, occupational therapy, physical therapy and other medical issues and are provided by licensed professionals.*
-

***Extra Tip:** Some individuals with cognitive impairment, especially those who do not recognize their limitations, may resist, or refuse the presence of a home care provider in their home, even if family members and health care professionals recognize the need for these services based on safety and ability. Ways to approach this situation vary, including starting with just a few hours at a time, or introducing the provider in a way more palatable to the individual. How this assistance is presented to the impaired individual is critical and more ideas are found in the **Re-sources** section .*



CONSIDER THIS: Hygiene: How to Help?

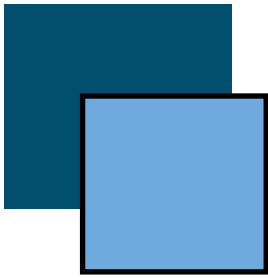
Often, impaired individuals may neglect, refuse, or resist bathing/showering; become confused about bathroom and hygiene products; present with clothes that are stained or dirty; and/or appear disheveled. This can be associated with procedural memory loss or lack of initiation, or in some cases, depression. This type of resistance can be quite frustrating for caregivers, who often find themselves in a difficult position of attempting to manage the impaired individual's hygiene.

The impaired individual may or may not be aware of their hygiene issues or may express lack of concern about it. Family members and caregivers can help with encouragement, and by providing routine, for example specific days and times for showering. Caregivers can also use gentle tones, and statements, rather than commands. There can be a number of reasons the impaired individual is resistant (embarrassment, anxiety, fear of falling, discomfort/pain, feeling overwhelmed), so identifying and addressing these can help as well. Promising an activity the loved one really likes after showering or bathing can help. Lastly, remember to leave plenty of time for bathing or showering, as it is a complex activity for the impaired individual and rushing will contribute to resistance.

There are several other techniques for assisting the caregiver when there is resistance from their loved one, and these are often presented in short practical videos produced by hands on experts in the field; check the [Resources](#) pages for links to these helpful instructions.

With regard to incontinence, there are several products on the market to assist with this problem that are respectful and hygienic. Sometimes it simply requires reminders or assistance to the toilet by the caregiver on a regular basis, as the impaired individual's brain may not recognize the physical alert that it is time to go.

Extra Tip: *Resisting assistance with hygiene issues is usually a sign of some concern the individual is unable or unwilling to disclose such as embarrassment at needing assistance or, in more advanced impairment, the inability to understand why they might need assistance. Discovering the “why” of resistance can often assist in the “what to do” quandary and eliminate arguments and frustration.*



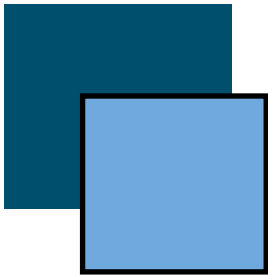
CONSIDER THIS: Legal Issues: Plan Ahead

Wills, powers-of-attorney, health care directives, and estate planning, if appropriate, should be considered as soon as possible after diagnosis. It's important to take care of these documents before the impaired individual is unable to understand what they are signing or is incapable of participating in the decisions and processes involved. Too often, families will wait until the loved one is in advanced stages of dementia, which contributes to confusion, legal complications, and family conflict.

Depending on the impaired individual's financial situation, some of the long term planning issues can become quite complicated and involve difficult conversations, but certified elder law attorneys and experienced estate planners can help facilitate the process. Aside from financial planning, there are several medical legal documents that are critical. Essential documents include a HIPAA Authorization Form, Medical Power of Attorney, and Advanced Care Directives, among others.

Additionally, at times an impaired individual may not have a family member who can make decisions, there may be conflict within the family regarding decisions, and/or the available family members are not willing or able to be a care manager. In these cases, there are established methods of appointing legal guardians who can act in the best interest of the patient. Information about this process is provided in the **Resources** section of this document. Elder care attorneys are also knowledgeable in this area.

Extra Tip: *You might be surprised at the number of laws and considerations when it comes to wills, powers of attorney and health care directives. If hiring an attorney is not an option for you, consider reputable on-line services, a few of which are listed on the **Resources** list.*



CONSIDER THIS: Living Arrangements

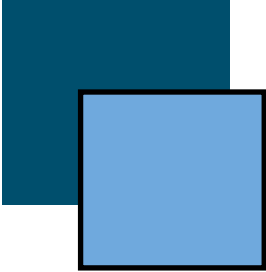
Living arrangements for individuals with cognitive impairment is perhaps one of the most difficult topics as dementia progresses. Families and the impaired individual can work together to make the best decisions for everyone, depending on the needs of the patient. Some families choose to help their loved one stay at home for as long as possible. Others provide for the impaired individual to live with an adult child, and some siblings share this responsibility. Still others might encourage their loved ones to consider some type of assisted living or memory care residences. *Once the needs and demands of the patient is more than the caregiver is able to provide without harm to themselves, it is time to consider alternatives.* The safety and physical ability of caregivers are important considerations when making decisions about living arrangements. Many mildly impaired individuals can live independently with minimal support for an extended period. However, over time the need for more assistance and support may be necessary.

There are many options available to meet the needs of caregivers, families, and patients. For those impaired individuals who are reasonably functional, one option might be an alert or other type of device that provides easy access to resources in emergencies. To help the impaired individual maintain independence, some caregivers have installed camera(s) with audio conversation abilities to monitor for safety and to provide directions on daily activities for the impaired individual remotely.

Caregivers who wish to keep the impaired loved one in their own home can access home health care services (see the related section in this document.) There are retirement communities with step down levels of care starting with independent living and moving to assisted living and then to full skilled nursing or memory units.

No one answer is right for every situation, and this is an area that requires planning for the future and giving consideration to all involved, including the patient.

Extra Tip: *As much as possible, include the impaired individual and other family members in the planning and decision-making process regarding living arrangements. The person experiencing dementia may resist changes in living arrangements, but consideration for patient safety, caregiver health, and practicality are important as well.*



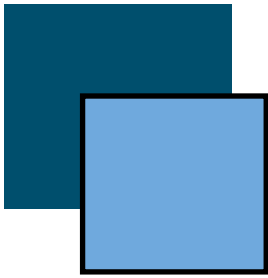
CONSIDER THIS: Meals, Nutrition, and Healthy Choices

Good nutrition is vital to brain functioning. Sometimes, as cognitively impaired individuals decline, activities like cooking, self-initiation to eat or eat healthily, remembering to eat, and healthy eating become challenging for both the impaired individual and caregivers. Consider enlisting services such as Meals on Wheels, visiting with a nutritionist or dietician, engaging the family in creating a schedule for meal delivery, or, if the individual can use the microwave, stocking the freezer with healthy frozen meals. Consult with your PCP or other provider, such as a dietician, regarding liquid supplements that might ensure nutrition is improved if the individual is consistently making poor food choices, not eating, or has diabetes. In some cases, it may be necessary for a verbal reminder that it is time to eat, either in person, with a phone call, or technology such as Alexa or other electronic devices.

Hydration is often an issue as well, as cognitively impaired individuals may not be as sensitive to thirst or not remember to drink enough water/liquids, becoming easily dehydrated. Ideas to help with this problem include keeping water close by, seeking out adaptive drinking aids, always supplying an appropriate beverage with meals, and making hydration breaks part of normal activities.

Also, consider other contributors to poor health such as alcohol intake, which should be minimal. It has long been reported that alcohol can damage brain cells, and for cognitively impaired individuals, every brain cell is essential so that the brain can compensate for losses as long as possible.

Extra Tip: *One of the hallmarks of dementia type illnesses can be lack of initiation to prepare meals, although the individual will eat what is prepared and presented. If you are a caregiver, keep a close eye on what and when the impaired individual is eating and drinking as they may not have the ability to recall or report adequately on this topic. Also, check the refrigerator for food that is past expiration.*



CONSIDER THIS: Medication Management

Multiple issues can and do arise regarding appropriate medication management for those with some type of dementia. A critical review of medications can be helpful at varying stages of cognitive impairment. Working with the primary care physician and other providers to review medications and supplements for efficacy, necessity, and interactions can assist in this process.

While the impaired individual should be encouraged to do everything he or she can, including taking medications at appropriate times and doses, many find it easier and safer to have a caregiver manage this. There are several options depending on level of cognitive challenge. Simple weekly manual pill organizers can be found at pharmacies and other retail stores with a variety of options. This makes it easier for the impaired individual, provided they are aware of date, day of the week, and time, to avoid taking too few or too many pills. For those who forget to take medication or are not oriented to time or day, automatic pill dispensers are available for a reasonable price as well. There are several varieties available that use a sound stimulus to alert the patient that it is time to take medication, dispenses the correct medication (s), and senses/reminds individual if medications are not taken from the dispenser. Depending on the number of medications, some impaired individuals will not remember if they took their pills, will put pills in their pockets or on the counter while getting water and then forget about them, or will take too many of one or more medications. Caregivers should be aware of these situations and monitor medication intake.

Beware, as well, of adding supplements without input from the medical team. Many supplements that advertise memory loss reversal and indicate they have had studies proving effectiveness are being marketed by companies who conducted the studies themselves, suggesting a conflict of interest. Some supplements can have harmful effects, and at the very least, be costly without real benefit.

Extra Tip: *Frequently, individuals with dementia may report they have taken their medication when they have not, usually due to memory challenges. Caregivers should monitor for compliance, and if there is a problem, take steps to ensure the impaired individual is taking medications as prescribed, in addition to ensuring prescriptions are refilled on time.*

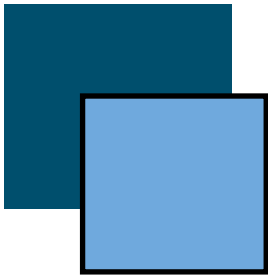
Medications used to treat patients with cognitive dysfunction have been studied mostly in patient with Alzheimer's Disease. Some of these medications may also be used in other forms of dementia. The following medications have been used in the treatment of Alzheimer's Disease for the past several years.

- **Acetylcholinesterase Inhibitors:** Acetylcholinesterase inhibitors are medications that can limit the breakdown of a neurotransmitter called acetylcholine, which is a chemical that is important in the transmission of messages between nerve cells. It is essential in the brain's ability to form memory. Medications in this category include Donepezil (brand name *Aricept*), Rivastigmine (brand name *Exelon*) and Galantamine (brand name *Razadyne*). Using these medications can help to lessen the speed of memory decline in patients with Alzheimer Disease. These medications do not improve memory and do not prevent the disease from progressing. Medications in this category are usually well tolerated, but they can have adverse side effects including, appetite change, and/or gastrointestinal upset including nausea or diarrhea. If taken before bed, these medications can also cause more vivid dreams during sleep. Acetylcholinesterase inhibitors can also aggravate heart rhythm conduction delays, and therefore an EKG is often ordered before starting the medication to ensure that the patient has a normal heart rhythm.
- **NMDA (N-methyl-D-aspartate) Receptor Antagonist:** Another category of medication used in the treatment of Alzheimer's Disease is an NMDA Antagonist. The medication in this category is called Memantine, (Brand name *Namenda*). This medication helps regulate the activity of a neurotransmitter called glutamate. Glutamate is vital for learning, memory, and overall cognitive function. This medication is typically well tolerated but can have potential side effects including sense of foggy and fatigue, constipation, and headaches.
- **Amyloid Targeting Therapies:** In recent years, there have been new medications approved in the treatment of Mild Cognitive Impairment and early Alzheimer's Disease. Medications in this category include Lecanemab (brand name *Leqembi*) and Donanemab (brand name *Kisunla*). These medications are monoclonal antibodies that target and help remove beta amyloid plaques in the brain that are associated with Alzheimer's Disease. These medications have shown some modest effect in slowing cognitive decline but they do not prevent the disease from progressing. These medications are given by IV infusions at routine intervals and are usually administered at an infusion center.

Patients must be screened by a qualified medical professional before starting the treatment, and will require ongoing surveillance while on medications. These medications have the rare risk of causing brain swelling and brain bleeding seen on brain scans. Adverse reactions include, allergic reactions, headaches, fatigue, and/or mild balance difficulty.

- **Other Medications:** There are medications that can be used to address mood disorders and insomnia problems associated with dementia. These medications can be prescribed by primary care, behavior health, or neurology providers. It is advised to have a cautious approach with any medications that could aggravate confusion, cause sedation, or increase the risk of falls. Often these medications should be started at a low dose and gradually increased to achieve benefit. Ongoing monitoring is recommended for tolerance, effectiveness, and adverse effects. Patients and family members should have good communication with their medical providers and have ongoing scrutiny and review of medications that are being taken.

If you find yourself caring for a relative with dementia, the chances are you'll need help.



CONSIDER THIS: Mental Health of Patients and Caregivers

Mental health challenges for cognitively impaired individuals can present in many ways. If there were preexisting conditions prior to the diagnosis, such as depression or anxiety, these conditions are likely to continue and increase in intensity at some point during the course of the disease. In some cases, depression becomes a part of the disease, even if there is no history of depression.

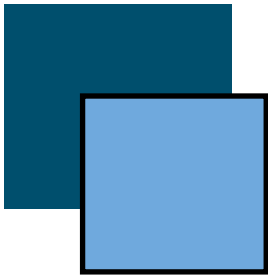
Anxiety can become paranoia, and delusional thinking or hallucinations can ensue in some cases. For others, a general sense of apathy might be prominent, wherein there is a lack of ability to initiate activities, which is not the same as a lack of motivation and is part of the disease process.

Regardless, there are medications that may help with these issues, and if the individual is in early to mid-stages, counseling can also be of assistance. Caregivers can monitor for these issues in their interactions with loved ones and friends, and report these to the medical team. In this way, quality of life can be enhanced for the impaired individual and caregiver.

Caregivers themselves are highly susceptible to developing depression and anxiety. Many studies indicate that caregiver mental and physical health decline over time unless the caregiver is engaging in significant self care. Counseling can be a good way to give caregivers an outlet for emotional issues associated with caring for a dementia patient and the changes associated with cognitive impairment. Caregivers should monitor their own mental health and not ignore signs such as lack of pleasure in life, general malaise, sadness that is pervasive, irritability, and difficulty with attention/concentration, which are only a few possible symptoms of distress.

More emphasis on the primary caregiver in research and services has been evident recently and continues currently. Terms like ‘anticipatory elongated grief’ and caregiver burnout, among others, are an attempt at recognizing the toll on caregivers and serve to assist in the creation of caregiver services.

Extra Tip: *Mental health services for patients and caregivers, either in person or via teletherapy, are available through a number of sources. Ask your health care provider such as your PCP or neuropsychologist for help in finding the right services. Some resources are also provided in the [Resources](#) section. Northshore Psychology Associates, LLC, is a premiere neuropsychological service in Northwest PA, and has multiple licensed and qualified providers offering cognitive evaluations and counseling.*



CONSIDER THIS:

Memory and Cognition: Compensatory Strategies

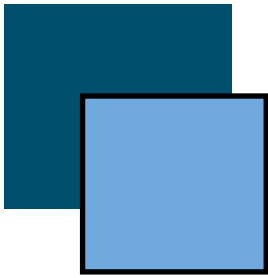
Individuals with mild to moderate experiences of neurocognitive impairment/dementia can benefit from assistance in developing strategies to help compensate for memory and communication challenges. These services are frequently provided by speech/language specialists who can work with a patient and family to develop cognitive exercises and strategies, sort of a physical therapy for the brain. For some, communication can be difficult as disease progresses so ideas for improved and meaningful conversation can be developed as well.

Your health care provider can refer you for these types of services, and a non-exhaustive list is included in the *Resources* section of this document. Additionally, books on this topic are listed.

Strategies for assists and reminders include specialized clocks that list day, date, and time; some of these even provide special alarms. Dry erase boards and calendars, a list of important phone numbers, photos with written names of family members, and even programming smart hubs such as Alexa, can also help caregivers and impaired individuals struggling with cognitive and memory challenges. For example, Alexa can be set to respond to “call my daughter” or to sound alarms at medication or meal times. Some smart watches can be programmed to call 911 if detecting a fall without response.

It’s important to keep these types of cognitive assistance tools in the same place so that multiple caregivers and the patient can refer to a ‘command center’ and to lead the impaired individual there repeatedly as part of a routine.

Extra Tip: *Speech and language therapists that work with cognitively impaired patients can assist in providing ideas and take-home exercises that are cognitively interactive, including both paper and electronic tablet applications.*



CONSIDER THIS:

Routine and Disruption

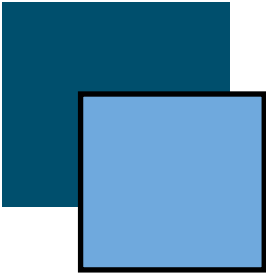
Many individuals in moderate to advanced stages respond positively to daily routines because these are familiar and feel safe. However, there are times when it is necessary to go outside of routine, such as a visit to a health care provider, a restaurant, or other public places. There are some preparatory steps the caregiver can implement to help make the excursion easier for both the impaired individual and caregiver.

Use good judgement on when to advise the impaired individual that something new is coming up. Sometimes, too much advance notice can create anticipatory anxiety or repeated questions. For some, knowing the day before an event is too much and disturbs sleep and mood. On the other hand, being given a surprise only a half hour before can be disturbing. Additionally, the reaction to an upcoming event can change for the patient over time, varying from apathy to anxiety to acceptance. The caregiver may become anxious as well, especially if there are behavioral disturbances that may be exacerbated by the change in routine.

Routine is important for gaining cooperation from the impaired individual as well, especially for encouraging hygiene activities, regular food consumption, regular hydration, and shifting sleep patterns. Although disrupting the routine can contribute to agitation or distress, this is usually temporary and a return to routine can help.

For public events, some caregivers carry a business card sized notice they can quietly give or show others who may interact with an impaired loved one in more advanced stages who may behave or speak in a manner incongruent with the situation. It reads “Please be patient. The person with me has Alzheimer’s disease and may have difficulties with confusion or controlling behavior/verbalization. Thank you for understanding.” Other caregivers have reported this type of approach doesn’t work for them or they dislike it, and simply point out to others that their loved one experiences cognitive issues.

Extra Tip: *When the impaired individual says inappropriate things in public, stay calm and do not scold, as this can exacerbate the situation. Gently guide them to a quieter area, distract them with a favorite topic, and discreetly apologize to bystanders. These outbursts are caused by brain changes, not personal choices.*



CONSIDER THIS: Safety and Supervision

With decreased cognitive awareness, a number of unexpected safety issues can emerge, which requires caregivers to assess abilities and determine intervention if needed. Some examples include, but are not limited to:

- Power tools, kitchen items, and other appliances that were once used with ease may become challenging or overwhelming to the impaired individual, and this can result in decreased safety. Removing the appliance or tool from the environment may be the best option.
- Use of the stovetop or oven is another area that will likely require assessment regularly. Disabling these functions may be required at some point.
- If the impaired individual is not permitted to drive, remove any possible access to a motor vehicle. Never assume the impaired individual will remember they cannot drive. In extreme cases, some caregivers have locked the car keys in a safe place.
- If there are weapons in the home, these should be locked away. Never assume the impaired individual will not access items in the home during periods of agitation, confusion, or emotional instability.
- Reassess, periodically, changes in ability regarding the use of tools, appliances, stove, oven, weapons and other items that could become potential hazards.
- Bathroom safety may require consideration as well, with regard to adding safety components such as grab bars, ensuring nonslip floors, and tub/shower entry.

Supervision of or assistance for impaired individuals regarding activities of daily living, such as personal hygiene, financial management, bill paying, medication management, cooking/meals, laundry, home cleaning and so on will be necessary at varying levels. Impaired individuals may not be aware of deficits, or may be wary to reveal deficits due to fear of losing independence.

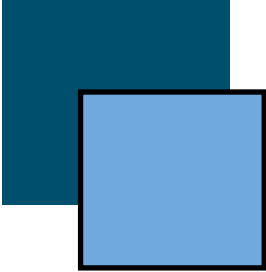
One way to determine the impaired individual's ability to use any potentially unsafe item or to perform a self care activity is to observe (intervening only if necessary for safety and effectiveness). This approach is better than asking "can you use the toaster?" or "are you OK in the shower?", as impaired individuals are not always aware or accepting of their abilities/limitations.

Discuss supervision/assistance issues with the impaired individual and observe functionality in these areas, and provide the level of supervision/assistance required. Supervision/assistance required will likely change over time and should be reviewed periodically.

Extra Tip: *Let the impaired individual do what he or she is able to do and offer assistance/structure as needed for accomplishing tasks safely. Try to avoid directives or commands, instead using suggestions, asking how you can help, and partnering to complete the task. Keep in mind that the patient may be slower at completing tasks, so patience is required.*

Safety and freedom are not opposites... The goal isn't zero risk (which is impossible), but reasonable safety that still allows living.

—Homewatch CareGivers



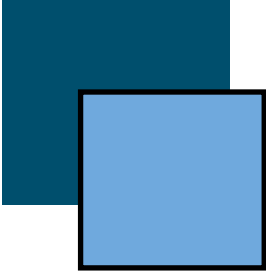
CONSIDER THIS: Scams and Fraud Risks

People living with dementia are prime targets for financial scams because the condition progressively impairs memory, impulse control, and critical decision-making faculties. Older adults are heavily targeted due to accumulated savings, good credit, and a tendency to be polite. When dementia is factored in, recognizing suspicious activity becomes profoundly difficult. This causes several issues that impact the impaired individual and family, including financial vulnerability, personal safety, and elevated stress. For most who are experiencing dementia, confusion at times is common and scammers have become quite expert at sounding legitimate and taking advantage of this confusion usually by phone, but also online.

On the other hand, the impaired individual may need a phone for safety reasons, be it a land line or a cell phone, so in most cases simply removing access to a phone or computer may not always be the best solution. Depending on the stage of impairment your loved one is in, you can take appropriate precautions regarding scam calls by working with the phone company, reducing unsolicited phone calls, posting signs near the phone reminding the individual not to share personal information with unknown callers, or using call blocker systems, of which there are a variety on the market you can access with a simple web search. Similarly, electronic notepad and laptop applications are available for limiting access, the most simple of these being to eliminate Wi-Fi access if necessary.

Caregivers can learn more about the most recent scam approaches at AARP, which updates this information regularly. More information can be found in the [*Resources*](#) section of this document. It is important for caregivers and family members to understand these risks and intervene as necessary.

Extra Tip: *Scammers don't always approach via telephone or electronically. It is also important to monitor the mail to take out very cleverly written and presented mail scam items to which the impaired individual may inadvertently respond.*

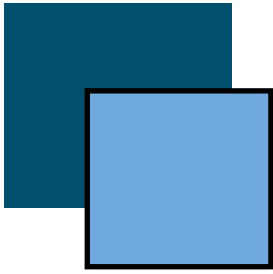


CONSIDER THIS: Sleep & Sundowning

Frequently, the brain mechanism responsible for circadian rhythm can be disrupted by cognitive impairment and dementia. For example, the impaired individual may want to nap frequently during the day and becomes alert and active during the night. Another example is an individual who arose regularly at 8 a.m. beginning to rise and be ready for the day at 4 a.m. In some types of dementia, sleep talking, sleep walking, and thrashing during dreams can be present. This can be difficult for caregivers, who need to get their own sleep in order to function in their role. There are several ideas suggested by the Mayo Clinic and Alzheimer's Association regarding managing sleep difficulties for impaired individuals found in the [*Resources*](#) section of this document.

Another well known term is 'sundowning'. This is the tendency, at some point, for individuals with certain types of dementia to become agitated later in the day. This is thought to be caused by the disruption of the impaired individual's internal sleep clock, dream/wake confusion, and/or fatigue. Not all people who experience cognitive impairment develop sundowning, but for those who do, there are several ways to decrease the behaviors and agitation associated with sundowning. A list of these is found in the [*Resources*](#) section of this document, and include planning doctor's and other appointments in the morning or early afternoon; establishing a routine and specific time for sleep and wake; and reducing stimulation in the evening.

Extra Tip: *Establishing a daily routine that involves balancing activities and avoiding naps if appropriate, along with a sleep preparation ritual can help some individuals with dementia to maintain a sleep-wake cycle that is more regular.*

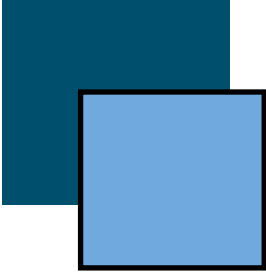


CONSIDER THIS: Travel Tips

For both caregivers and loved ones with MCI or dementia, it sometimes seems easier to avoid the logistics of travel, but with some extra preparation, planning, and appropriate time estimates, engaging in travel can still be rewarding and fun. Here are a few tips for making a trip work for you:

- **Plan Ahead:** Ask what type of trip would work for all of you? For example, familiar destinations are probably better than major time zone changes and destinations even the caregiver is unfamiliar with.
- **Allow More Time:** During trips, remember that the individual with MCI or dementia may move slower depending on physical condition and stage of impairment. To avoid being impatient and rushing your loved one, plan for more time for every travel step and activity, along with planning rest times. Avoid overpacked itineraries.
- **Routine/Stimulation:** As best as possible, stick to a general routine during the trip and avoid over stimulation wherever possible. This may be difficult at times, so be prepared to make adjustments to your trip and activities.
- **Safety:** For those with more advanced cognitive impairment, provide a wearable tracker in case you are separated. Let the airlines and hotels know in advance if there are accommodations needed, such as early boarding, quiet rooms, wheelchair, transport.
- **Pack These Extras:** Carry documentation of medications, emergency contacts, physician's note if needed, insurance cards, comfort items for caregiver and loved one, and ensure the individual with MCI or dementia has adequate identification with them at all times.

Extra Tip: *Establishing a daily routine that involves balancing activities and avoiding naps if appropriate, along with a sleep preparation ritual can help some individuals with dementia to maintain a sleep-wake cycle that is more regular.*



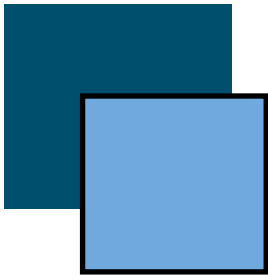
CONSIDER THIS: Wandering and Disorientation

Some impaired individuals, depending on disease progression, will want to leave their environment but are not capable of finding their way back or may become confused and disoriented. This can occur at any stage in the neurodegenerative disease. This is commonly referred to as wandering and occurs in a large percentage of individuals with dementia at any stage. It is a serious safety risk that should be monitored regularly.

Reasons wandering occurs include searching for families, reliving past routines, physical needs, boredom and restlessness, and environmental overwhelm. Early warning signs include pacing near the door, speaking of past responsibilities repeatedly (going to work, picking up the children, visiting parents),

There are several tools to help caregivers and patients manage this situation and support safety. Trackers can be placed in/on shoes. If the impaired individual carries a phone, phone tracking software is available. Identification bracelets and watches with location and ID technology are another tool. Door alarms are yet another way to help the caregiver be aware if the impaired individual is leaving the home. Wandering can quickly become a dangerous situation, and caregivers are rightly advised to make this issue a priority.

Extra Tip: *Some warning signs of wandering include the impaired individual stating “I want to go home” when they are already at home, “I want to go see my sister” when the sister is remote or deceased, “I have to go to work” when they are no longer working, and pacing/agitation near the door. There is always a reason in the mind of the impaired individual to be leaving. Caregivers can explore that reason and offer alternative scenarios, for example, responding to “I want to go home” by asking them to talk about their home and/or assuring them of their safety and security.*



CONSIDER THIS: Resources

*****This is not a complete list, nor is this an endorsement of any provider, website, law firm, product, or other services. The [Resource](#) list is a starting place and provided for exploratory and informational purposes only.*****

Community and General Resources/Information

Greater Erie Community Action Committee (GECAC)

814-459-4581

www.gecac.org

UPMC

<https://www.upmc.com/services/seniors>

Independent Council on Aging, Erie PA

<https://www.icaerie.org>

Alzheimer's Association

www.alz.org

LECOM

<https://lecomisaging.com/>

Allegheny Health Network

<https://www.ahn.org/services/neuroscience/conditions/dementia-alzheimers-disease>

National Institute on Aging

<https://www.nia.nih.gov>

Life Northwestern PA

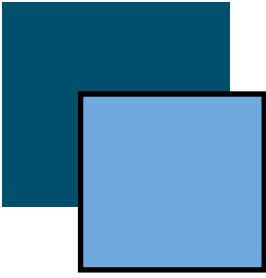
<https://www.lifenwpa.org/>

Activities and Cognitive Exercises

The Memory Café

Unitarian Universalist Congregation of Erie

<https://uuerie.org/connection/memory-cafe/>



CONSIDER THIS: Resources

Activities and Cognitive Exercises, continued

Phone apps for dementia patients

<https://afscenter.org/dementia-phone-apps/>

Adult Day Care

<https://www.aging.pa.gov/local-resources/Pages/Adult-Day-Center.aspx>

<https://www.alzstore.com/alzheimers-dementia-activities-s/1673.htm>

<https://aarp.org/stayingsharp>

<https://www.aging.pa.gov/local-resources/Pages/Adult-Day-Center.aspx>

Assisted Living, Skilled Nursing, Retirement Communities, Home Care, Independent Living

<https://www.communityresourcefinder.org/ProviderSearch/>

<https://www.aging.pa.gov/aging-services/caregiver-support/Pages/default.aspx>

Automatic Pill Dispensers/Medication Management

<https://medbox.com/simplifying-medication-management-for-seniors-a-guide-to-pill-dispensers/>

<https://www.cvs.com/content/pharmacy/simplesdose>

<https://www.carefillpack.com/>

<https://www.medicap.com/services>

<https://herohealth.com/>

Behavior and Personality Changes

<https://www.nia.nih.gov/health/managing-personality-and-behavior-changes-alzheimers>

<https://www.agingcare.com/articles/handle-dementia-fueled-outbursts-148106.htm>

10 Tips for Responding to Dementia Anger, Dementia Careblazers

<https://www.youtube.com/watch?v=OuCSkaXX7pQ>

Books/Video Tips

Practical Nutrition and Hydration for Dementia-Friendly Mealtimes, *Lee Martin*

The 36 Hour Day, *Nancy Race, MA & Peter Rabins, MD, MPH*

<https://www.irisseniorliving.com/blog/the-best-books-to-help-you-learn-about-dementia>

Looking Through The Window At Dementia: The Caregivers Handbook to Understanding Dementia, *Laura Banner*

When Waves Rise: Navigating Difficult Moments Associated with Dementia, *Sarah Viola, OTR*

The Spectrum of Hope, *Gayatri Devi, MD*

The DICE Approach, *Helen Kales, MD, Laura Gitlin, PhD*

Living With Mild Cognitive Impairment, *Nicole Anderson, PhD et al.*

There are many, many other books on dementia and caregiving and you can do an Amazon search to find them.

<https://www.youtube.com/rachaelwonderlin>

<https://www.facebook.com/BeLightCare/>

Caregiver Support

<https://www.aarp.org/caregiving/basics/info-2019/caregiver-glossary.html>

https://www.alz.org/events/event_search?etid=2&cid=0

<https://www.alz.org/help-support/caregiving>

<https://www.belightcare.com/services>

<https://www.upmc.com/services/seniors/resources-for-caregivers/social-emotional-support/support-group-location-search/dementia-caregiver-support-groups>

<https://www.aplaceformom.com/caregiver-resources/articles/caregiver-support-groups>

www.caregiver.org

<https://joannadementiaexpert.com/>

<https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout#symptoms-and-causes>

<https://www.stmaryshome.org/our-services/respite-care>

<https://www.facebook.com/nealkshahcareyaya/videos/>

Alzheimer's Association Caregiver Support Group

<https://events.eriibrary.org/event/15849227>

Lincoln Community Center Library
1255 Manchester Road
Erie, PA 16505
Phone: 814-838-9191

Communication Strategies

<https://newsnetwork.mayoclinic.org/discussion/how-to-improve-communication-with-a-loved-one-who-has-aphasia/>

<https://teepasnow.com/>

<https://www.alz.org/help-support/caregiving/daily-care/communications>

https://www.alz.org/alzheimers-dementia/what-is-dementia/related_conditions/anosognosia

<https://www.agingcare.com/articles/anosognosia-dementia-patients-cant-recognize-impairment-210090.htm>

<https://bestreviews.com/electronics/clocks/best-memory-loss-clocks>

<https://careforth.com/blog/dementia-alzheimers-or-memory-care/>

Crisis and Warm Lines

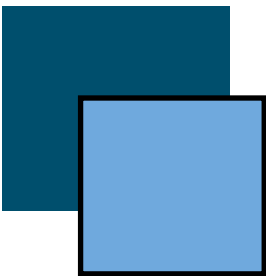
Alzheimer's Association Hot Line (general information/resource guidance)	800-272-3900
Erie County Crisis Line (emergency situations)	814-456-2014
National Hotline (emergency situations)	800-300-9558
Warm Line (non-emergency situations, extra support)	877-550-4007
National Suicide Hotline	988

Course and Timelines

Alzheimer's Stages

<https://www.webmd.com/alzheimers/guide/alzheimers-disease-stages>

<https://www.hopkinsmedicine.org/health/conditions-and-diseases/alzheimers-disease/stages-of-alzheimer-disease>



Course and Timelines, continued

Frontotemporal Dementia

<https://www.hopkinsmedicine.org/health/conditions-and-diseases/dementia/frontotemporal-dementia>

Lewy Bodies Dementia

<https://www.verywellhealth.com/lewy-body-dementia-stages-progression-98735>

Parkinson's Disease

<https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview>

<https://my.clevelandclinic.org/health/diseases/parkinsons-dementia>

Driving/Transportation

<https://www.dot.state.pa.us/public/DVSPubsForms/BDL/BDL%20Publications/Pub%20345.pdf>

<https://dailycaring.com/4-tips-to-get-an-elderly-person-to-stop-driving/>

<https://dailycaring.com/8-ways-to-stop-an-elderly-person-from-driving-when-all-else-fails/>

<https://www.aarp.org/caregiving/home-care/info-2020/transportation-services.html>

Transportation Solutions

4202 Peach Street

Phone (814) 833-2301

<https://www.transportationsolutionserie.com/>

Erie County Errand Service

(814) 840-1811

<https://eriecountyerrandservice.com/>

National Transportation Evaluation Database (National list of providers of driving evaluations)

<https://www.ADED.net>

<https://www.pa.gov/agencies/dmv/driver-services/mature-drivers/mature-driver-improvement-course>

<https://www.pa.gov/agencies/dmv/resources/driver-safety-and-vehicle-maintenance/mature-driver-safety-tips>

Educational Resources

Alzheimer's Association
800-272-3900 Helpline
www.alz.org

<https://www.alz.org/alzheimers-dementia>

Vascular Dementia
<https://www.nia.nih.gov/health/vascular-dementia/vascular-dementia-causes-symptoms-and-treatments>

Frontotemporal Dementia
<https://www.mayoclinic.org/diseases-conditions/frontotemporal-dementia/symptoms-causes/syc-20354737>

Lewy Bodies Dementia
<https://www.nia.nih.gov/health/what-lewy-body-dementia-causes-symptoms-and-treatments>
www.lbda.org

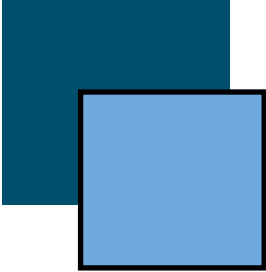
Interacting with Dementia Patients
<https://teepasnow.com/> (Positive Approach™ for interacting with dementia patients)

Mayo Clinic
<https://www.mayoclinic.org/diseases-conditions/dementia/symptoms-causes/syc-20352013>
<https://www.mayoclinic.org/diseases-conditions/mild-cognitive-impairment/symptoms-causes/syc-20354578>

National Institute on Aging
www.nia.nih.gov

Alzheimer's Research and Resource Foundation
<https://institution.ararf.org/>

Research Institute on Aging By Us For Us
www.the-ria.ca/resources/by-us-for-us-guides/
<https://www.alzheimers.org.uk/about-dementia/stages-and-symptoms/dementia-symptoms/why-person-with-dementia-might-be-walking-about>



Educational Resources, continued

A Quick Look at Alzheimer's (Series of 5 videos, 2-3 minutes each, providing introductory education)

<https://www.agingresearch.org/video/quicklookatalzheimers1/>

<https://pmc.ncbi.nlm.nih.gov/articles/PMC7377549/>

<https://www.webmd.com/alzheimers/cm/caregiver-plans-alzheimers>

<https://pmc.ncbi.nlm.nih.gov/articles/PMC7377549/>

<https://www.webmd.com/alzheimers/features/creative-outlet-agitation-alzheimers>

<https://www.health.com/condition/alzheimers/how-caregivers-can-manage-alzheimers-disease-changes>

Elder Law/Senior Attorneys/Estate Planning

Elderkin Law Firm 814-456-4000

Knox, McLaughlin, et al 814-459-2800

Steadman Law Office 814-774-2628

Quinn Law Firm 814-833-2222

<https://www.heritageelderlaw.com/>

<https://www.consumerreports.org/estate-planning/what-to-know-about-making-an-online-will/>

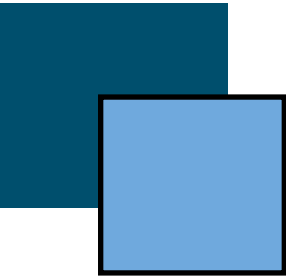
<https://www.justia.com/lawyers/elder-law/pennsylvania/erie-county>

<https://eriefamilycenter.org/guardianship/>

Certified Elder Law Attorneys (CELA), can be found through National Elder Law Foundation at

<https://www.getelderlaw.com/>

<https://www.agingcare.com/articles/legal-documents-to-make-healthcare-decisions-for-your-parent-146623.htm>



Fall Prevention and Alert Systems

<https://cdn.alzheimer.mb.ca/wp-content/uploads/2025/06/2014-Dementia-Fall-Risk-Checklist-template.pdf>

<https://www.alzstore.com/senior-safety-fall-prevention-products-s/1827.htm>

<https://www.homewatchcaregivers.com/blog/prevention-safety-tips/be-aware-of-fall-risks-for-seniors/>

<https://www.consumerreports.org/medical-alert-systems/how-to-choose-a-medical-alert-system-a1228040748/>

Hygiene

<https://dailycaring.com/7-tips-to-get-someone-with-alzheimers-to-take-a-bath/>

<https://www.alz.org/help-support/caregiving/daily-care/bathing>

<https://www.youtube.com/watch?v=sl3Dc1kERto>

The link above is a UCLA produced video on ways to encourage and assist in bathing

<https://thebluehug.com/>

Location and Medical Alert Devices

<https://www.alzheimers.net/8-8-14-location-devices-dementia>

<https://www.alzstore.com/alzheimers-dementia-wandering-s/1828.htm>

<https://www.medicalalertbuyersguide.org/articles/the-best-gps-trackers-for-dementia-patients/>

<https://www.usnews.com/360-reviews/services/medical-alert-system>

<https://www.medicalalert.com/>

<https://www.amazon.com/Amazon-vibrant-helpful-routines-Charcoal/dp/B09B8V1LZ3?th=1>

<https://www.amazon.com/Alexa-Emergency-Assist-Monthly-auto-renewal/dp/B0CC5WMQFH>

Meals on Wheels

<https://mealsonwheelserie.org/>

Erie County phone 814-452-6930

Corry phone 844-378-0202

Mental Health/ Services

<https://www.psychologytoday.com/us/therapists/pa/erie-county>

<https://thrivetherapyspace.com/>

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

Nutrition and Hydration

<https://www.alz.org/help-support/caregiving/daily-care/food-eating>

Scams and Fraud

<https://www.brainandlife.org/articles/elderly-parents-or-family-members-with-cognitive-impairments-are-especially/>

<https://www.aarp.org/money/scams-fraud/>

<https://www.aarp.org/money/scams-fraud/trending-scams/>

<https://www.aarp.org/money/scams-fraud/protecting-yourself-from-criminals/>

Sleep Changes/Disturbances

<https://www.mayoclinic.org/healthy-lifestyle/caregivers/in-depth/alzheimers/art-20047832#:~:text=Help%20the%20person%20relax%20by,venlafaxine%2C%20can%20lead%20to%20insomnia.>

<https://www.alz.org/alzheimers-dementia/treatments/for-sleep-changes>

<https://www.alz.org/help-support/caregiving/stages-behaviors/sleep-issues-sundowning>

Speech/Language Therapy Providers (Cognitive Rehab)

UPMC Speech & Language

<https://www.upmc.com/locations/hospitals/hamot/services/speech-pathology>
814-877-2537

Saint Vincent AHN Rehab Solutions

1910 Sassafras St, Erie PA 16503

814-452-5231

Treatment/Clinical Trials

<https://www.alz.org/alzheimers-dementia/treatments>

https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials

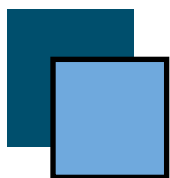
Wandering Behavior

<https://www.upmc.com/services/seniors/resources-for-caregivers/wandering-tendencies-patients-alzheimers-dementia>

<https://newsnetwork.mayoclinic.org/discussion/alzheimers-and-dementia-understand-wandering-and-how-to-address-it/>

More Resources

[illegible]



Consider This: A guide for patients and families experiencing cognitive impairment, memory loss, and/or dementia

