

Taking Care: Managing Dementia with Dignity



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Taking Care: Managing Dementia with Dignity Handbook

Table of Contents

Section One—

Dementia and Alzheimer’s Disease: The Basics 1

What is Dementia? 2

What is Mild Cognitive Impairment? 2

Causes of Dementia 3

Progression of Dementia 3

Warning Signs: When to See a Doctor for Memory Loss 5

Diagnosing Dementia 6

 Question 1. Is Memory Loss Present? 6

 Question 2. What Could Be Causing the Memory Loss and Other Changes? 7

 Question 3. Are the Symptoms and Findings Consistent
 with What We Know About a Particular Dementia? 8

Treating Dementia 8

 Medications 8

 Types of Medications for Dementing Illness 9

 Cognitive Enhancers 9

 Antidepressants 10

 Anxiolytics 10

 Medications for Sleep 10

 Atypical Antipsychotics 10

 Clinical Studies and Research 11

Common Dementing Illnesses: The Basics of Care 12

 Amnesic Mild Cognitive Impairment 12

 Alzheimer’s Disease 12

 Early Stages 12

 Moderate Stages 13

 Behaviors in Moderate Stages 14

 What Triggers and Prevents Problem Behaviors and How to Manage Them 15

 Fatigue 15

 Changes in Environment, Routine, or Caregiver 16

 Overwhelming or Misleading Stimuli 18

 Loss of Meaningful Activities 18

 Creating Too Much Demand 19

 Illness 21

 Advanced Stages 22

 Engaging Hospice Services 23

Section Two—

Non-Alzheimer's Dementias	25
Why Bother?	25
Dementia with Lewy Bodies	26
What is Lewy Body Disease?	26
What is a Lewy Body?	26
Movement	27
Task Performance.	27
Autonomic Nervous System	27
Medications: Increased Sensitivity	29
Perception	30
Assessing Visual Perception	30
Psychosis in Dementia with Lewy Bodies.	32
Apathy	32
Sleep Changes	33
Memory	33
Medical Treatment for Parkinsonian Features and Behaviors.	33
Non-Pharmacologic Treatment of Dementia with Lewy Bodies.	34
Helping the Diagnostician	34
Frontotemporal Dementia	34
Frontotemporal Dementia: Behavioral Changes in Middle Age	35
What Does Frontotemporal Dementia Look Like?	35
Diagnosing Frontotemporal Dementia	36
If You Suspect Frontotemporal Dementia.	36
Behavioral Changes with Frontotemporal Dementia	37
Vascular Dementia	37

Section Three—

Care Issues as the Disease Progresses	39
Developmental Regression	39
Fear of Abandonment and Nursing Home Placement.	39
Decision-Makers	39
What is a Decision-Maker? How Do We Find One?	39
What is a “Durable” Power of Attorney? How Does It Differ from a Regular Power of Attorney? . . .	42
Who Becomes a Durable Power of Attorney?	42
What are Common Health Decisions for Someone with Moderate to Advanced Dementia?	43
Safety Issues	44
Safety is a Concern Throughout the Illness When a Person Has Dementia	44
Early Disease: Examples of Common Safety Issues Reported by Families.	44
Financial Issues	44
Will My Loved One Become Violent?	45
When Aggression Starts	47
Are You Safe?	47

Live-Alones (People with Dementia Who Live Alone)	49
What Can a Family Do to Help a Person with Dementia who is Living Alone?	50
Driving	52
Providing Care with Dignity: Day-to-Day with Dementia	52
Basic Environmental Safety	52
Common Questions and Answers	53
“Why Does My Person Ask the Same Question Over and Over?”	53
“Why Can’t I Get My Person to Sleep at Night?”	53
“My Person Lies All the Time, Making Up Stories We Know Aren’t True.”	53
“How Can I Convince My Mom That Her Parents Are Dead?”	54
“I Want a Candy Bar, NOW!”	54
“Everything I Say Seems to Lead to an Argument! How Can I Stop This Arguing?”	54
“I Am Not Going to Adult Day Programming! That Is for Old People!”	55
“She Wants to Wear the Same Clothing Day After Day.”	55
“Why Is She Resistant to Bathing?”	55
“Why Is He Hiding Things and Accusing Me or Others of Stealing?”	56
 Section Four—	
Caregiving	57
Becoming a Caregiver	57
Accepting Help	57
Taking Care of Yourself	59
Finding Help from Family	59
Hiring In-Home Help	60
Adult Day Programs	60
Assisted Living and Memory Care	61
How to Make the Move to Assisted Living	62
Start the Conversation Early (Depending on the Stage of Memory Loss)	62
Choose a Community Specializing in Memory Care	63
Consider Visiting the New Assisted Living Community Together Before Moving Day	63
Schedule the Move for Their “Best Time of the Day”	64
Bring a Simple Collection of Favorite Things	64
Communicate with the New Caregiving Staff	64
 Section Five—	
Finding Help: Dementia Resources and Organizations	65
Local and National Alzheimer’s Disease and Related Dementias Resources	65
Dementia-Specific Products	66
 Section Six—	
References and Suggested Reading and Viewing Lists	67
References	67
Suggested Reading List	67
Suggested Viewing List	67

Appendix 1—

Signs to Watch For in People who Live Alone or Who are at High Risk 68

Classification 68

Reported or Observed Conditions 68

Observation Cues 70

Notes 72

Abbreviations

AD - Alzheimer's disease

CPR - cardiopulmonary resuscitation

CT - computed tomography

DLB - dementia with Lewy bodies

DPOA - durable power of attorney

FTD - frontotemporal lobar degeneration

MCI - mild cognitive impairment

MRI - magnetic resonance imaging

NMS - neuroleptic malignant syndrome

PET - positron emission tomography

POA - power of attorney

PPD - Parkinson disease dementia

VaD - vascular dementia



Introduction

One of the most daunting challenges affecting our society is the increasing rate of Alzheimer's disease and related dementias among our population. Alzheimer's disease is a national crisis. About 5.4 million Americans are living with Alzheimer's disease today. By 2050, that number could exceed 16 million. Deaths from AD have increased by 89% since 2000. It is currently the sixth leading cause of death in the United States.

Every 66 seconds someone receives this devastating diagnosis. Unfortunately, in most cases after receiving the diagnosis, they receive little else in terms of support or guidance.

At Barrow Neurological Institute, we are assembling a world-class team of clinicians and researchers focused on fostering innovation in the field of Alzheimer's research, while shifting the treatment paradigm. We continue to have an unwavering commitment to our patients and our community.

The vision of the Barrow Alzheimer's and Memory Disorders Program is a bold one...

End Alzheimer's disease, but do not forsake those who are currently suffering its effects.

Our vision and promise to our patients and community began with a focus on groundbreaking research and building a patient-centered care model, complete with clinical support and wraparound services.

We have created this caregiver guide in an effort to provide much-needed guidance to caregivers struggling with the day-to-day challenges of living with dementia. It is intended to help the person with dementia and their caregiver understand the basic principle of diagnosing, managing, and living with this disease. We hope that you find this information useful. Additional information regarding particular topics of interest can be found on our website: BarrowNeuro.org/Memory.



SECTION ONE—

Dementia and Alzheimer's Disease: The Basics

1

One of the most feared conditions among adults is memory loss. When combined with symptoms such as changes in language abilities, functional abilities, and personality, memory loss may indicate a person has a brain disease. The disease would be expected to worsen over time, removing the ability to live independently, drive, and maintain employment. It could eventually lead to placement in a nursing home or other residential institution. The collective symptoms of these brain diseases are called “dementia.” Illnesses that cause dementia are called “dementing illnesses.” Most dementing illnesses are very challenging to treat or cure.

People with the disease and their families struggle to find helpful information to assure their care needs are understood and met. For many, there is a fear of being judged as “crazy” or “incompetent.” There is often a sense of stigma, concern of mistreatment, and fear of abandonment to the primitive care systems as was the standard of care in the mid-20th century. Families often ask, when their person will become violent, not understanding that aggression is rare.

Dementing illnesses often change the person's ability to interpret who or what they see, hear, and taste from sensory input. In short, everything the person understands about their surroundings is changing. It is safe to assume this condition would be upsetting, even frightening. In today's care environments, professionals and trained direct-care providers try to help the person and family to understand what they are feeling and seeing in order to provide context. Activities and interests become the focus of care to ensure a loved one's distinct personality is maintained. This normalized focus of care maintains a sense of the person's dignity and value.



As dementing illnesses become apparent, it is critical for the person with the illness and their loved ones plan for care and for changing legal and financial needs. There is a tremendous amount of information published about dementing illnesses. Sifting through it to get the information you need can be a challenge – especially if you are providing care at the same time. The physicians at Barrow Neurological Institute want you to have ready access to the information you need to cope with your loved one's illness.

This booklet was developed by dementia care experts at Barrow to guide you through the stages of dementing illnesses using the best possible care techniques, which have been carefully researched. It has been given to you because someone you love has symptoms of a dementing illness, such as loss of memory for recent events or difficulty with reading comprehension or using language. The purpose of

the book is to help you understand the basics of dementing illness and caregiving, prepare for “critical tasks” that arise, resources, familiarize yourself with resources and community services, and received answers to commonly asked questions. There are many books published on dementia, AD, and related disorders. This caregiver booklet was developed to supplement your understanding and to help you discuss your experiences with your Barrow care team. In addition, there are blank pages for you to record your loved one’s journey through dementia for discussions with his or her providers.

What is Dementia?

“Dementia” is an umbrella term describing a broad category of symptoms indicating there is an illness damaging the brain (Figure 1). It is not a specific diagnosis. The term simply indicates that there are changes in thinking (cognitive changes) that are affecting a person’s ability to function as they did before. About 47.5 million people worldwide suffer from dementia, with 7.7 million new cases diagnosed each year.^[1]

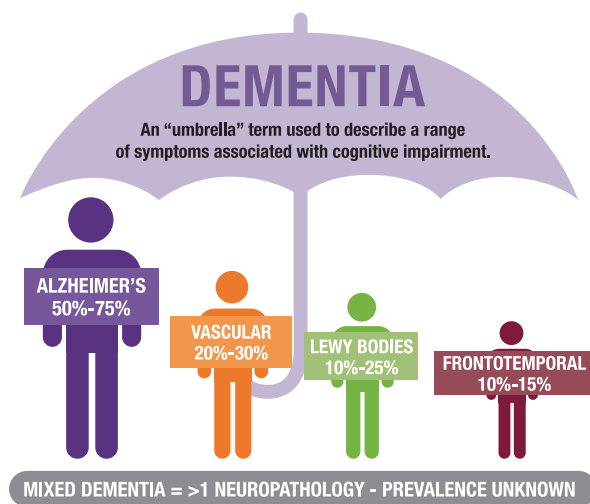


Figure 1. Portions of the population with different types of dementia.

There are four types of symptoms of dementia: 1) personality changes; 2) loss in the ability to think, learn, and remember; 3) a slow progressive decline in the ability to perform tasks (we call this inability “loss of function and executive abilities”); and 4) a diminishing ability to tolerate stress. Symptoms of dementia vary depending on the places in the brain where the disease occurs, the person’s personality, the person’s culture, the environment where they live, and what is happening around them.

What is Mild Cognitive Impairment?

Mild cognitive impairment (MCI) is a term used to describe a stage of illness that precedes dementia. During this stage, changes in cognitive functions such as memory, language, reasoning, attention, or judgment may be present. However, they are not yet severe enough to significantly affect daily function.

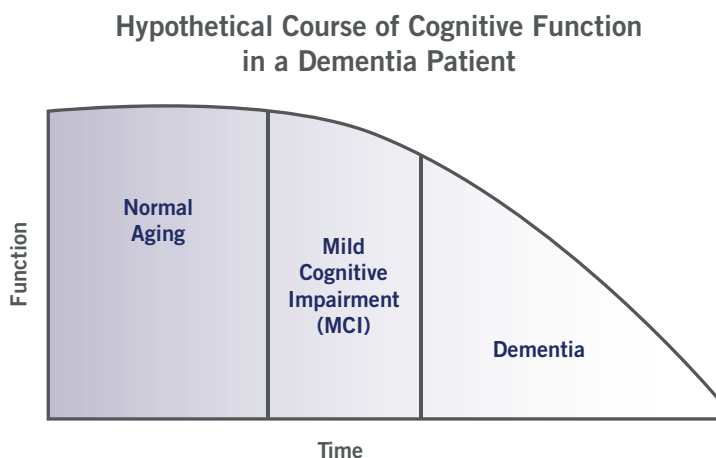


Figure 2. As some people age, their memory, language skills, and judgement could decline as shown.

Every type of dementia goes through an MCI stage, though not everyone with MCI will go on to develop dementia (Figure 2). There are currently no approved treatments for MCI, but there is mounting evidence that medications used to treat dementia, as well as lifestyle modifications made at this early stage of illness, can be helpful in slowing its progression to dementia.

Causes of Dementia

Many conditions can cause dementia; the most common is AD. Although every person with AD develops dementia, not all people with dementia have AD. There are dozens of non-AD dementias, some of which can be treated. Yet, the diagnosis is often overlooked after an initial evaluation. People with non-AD dementia may appear to have similar symptoms and needs as someone with AD, but their personal needs and responses to medication and interventions often differ greatly from people with AD. In this booklet, we will focus on four diseases that cause dementia:

1. AD: 5.7 million in the United States (U.S.)
2. Dementia with Lewy bodies (DLB): 1.4 million in the U.S.
3. Frontotemporal lobar degeneration (FTD): 60,000 in the U.S.
4. Vascular dementia (VaD): 1.3 million in the U.S.^[2]

In brain diseases, the symptoms vary depending on the location of the damage. To complicate matters, each of the diseases listed above presents in several different ways because symptoms occur in different areas of the brain. This issue is especially true of FTD. In FTD, the initial symptoms are either a change in behavior or changes in the ability to use language. This condition changes over time to having both language and behavioral symptoms. In addition, people with FTD may develop motor symptoms or Parkinsonism.

Another issue is the purity of the disease presentation. It is not uncommon for people to have more than one dementing illness, such as having AD and a history of strokes. Multiple dementing conditions can result in a confusing clinical picture and may require management by a physician specializing in geriatric psychiatry, behavioral neurology, neuropsychiatry, or geriatrics. These specialists have extensive training in the management of complex dementias. The doctors at Barrow are specialized in these areas.

People with different types of dementia have different care needs. The symptoms and progression of specific dementias may be very different than those of AD. If we provide care to everyone with dementia the same way we care for people with AD, it can result in a poor fit and increased behavioral symptoms.



Progression of Dementia

Most dementias, including AD, are neurodegenerative in nature and will worsen over time despite treatment (Table 1). How quickly this degeneration occurs may vary from person to person. People with AD typically live eight to 10 years but may live as long as 20 years.

Table 1. Stages of Cognitive Impairment

MCI	MILD DEMENTIA	MODERATE DEMENTIA	ADVANCED DEMENTIA
MEMORY AND THINKING			
<ul style="list-style-type: none"> • Difficulty with short-term memory • Poor judgment • Poor concentration 	<ul style="list-style-type: none"> • Difficulty with short-term memory • Poor judgment • Poor concentration 	<ul style="list-style-type: none"> • Difficulty with short and long term memory • Forgets autobiographical history • May forget friends • Poor judgment • Word finding difficulty • Poor concentration 	<ul style="list-style-type: none"> • Severely impaired short- and long-term memory • May not recognize family or self in the mirror
LANGUAGE			
<ul style="list-style-type: none"> • Word finding difficulty 	<ul style="list-style-type: none"> • Word finding difficulty 	<ul style="list-style-type: none"> • Loses ability to understand spoken language/words • Loses ability to read • Loses ability to formulate sentences • Uses vague words 	<ul style="list-style-type: none"> • Unable to complete thoughts or carry on a meaningful conversation
MOOD			
<ul style="list-style-type: none"> • May be depressed, irritable, or socially withdrawn 	<ul style="list-style-type: none"> • May be depressed, irritable, or socially withdrawn 	<ul style="list-style-type: none"> • May be depressed, irritable, or socially withdrawn • May display less emotion 	<ul style="list-style-type: none"> • Socially withdrawn • Focused on internal world • Difficult to engage
FUNCTION			
<ul style="list-style-type: none"> • Intact though may exert more time or effort on complex tasks 	<ul style="list-style-type: none"> • Difficulty organizing tasks • Difficulty managing finances • Difficulty managing medications • May get lost while driving • Difficulty initiating activities 	<ul style="list-style-type: none"> • Forgets to eat or drink • More difficulty using utensils • Forgets to bathe or misses steps when bathing • May become afraid of water (bath/shower) • Grooming becomes more lax • May forget to shave or brush teeth • Difficulty sequencing steps to dress self • Bowel/ bladder incontinence may emerge 	<ul style="list-style-type: none"> • Totally dependent on others for bathing, dressing, grooming, toileting, and feeding • May forget to chew food or swallow • May lose ability to control muscles or coordinate movements • Forgets how to walk without help

Warning Signs: When to See a Doctor for Memory Loss

The earlier a dementing illness is diagnosed, the better. Research tells us that while foods and supplements have shown little value in treating dementia, some exercise and activity programs have shown to slow the disease progression and enhance the quality of life. Prescription medications such as cholinesterase inhibitors may also work to stabilize symptoms in some people. Both exercise, activities, and medications work better when started early in the disease. In addition, the person with the disease will have better insight early on, thus be able to participate in therapy, programming, and clinical drug trials. Once the symptoms are more severe, the areas of the brain damage are believed to be too impaired to improve.

The other reason for early diagnosis is to use the early phases to plan for the future stages of the disease. The caregiver should help their loved one to:

- Find out who they want to make decisions for them if and when they are unable, and with whom they want to establish durable powers of attorney.
- Determine how their finances will be managed.
- Plan for long-term care. Medicare does not pay for long-term care. Very few people want to think about long-term care early in the disease, yet it can save the family considerable money. However, long-term care insurance must be applied for and purchased before seeking a diagnostic evaluation for AD or non-AD dementia.
- Determine what types of services they would prefer, for example, in-home versus adult daytime health services, and tour different types of care settings. Most people prefer to remain at home with family caregivers; however, as the disease progresses, that may not be possible. Spouse caregivers are often the same age as the person with dementia and have pre-existing medical conditions. Other family members work or live far away.

Families often disagree about where a person should live and who will provide care. This situation could include airing longstanding conflicts, especially about how the family resources will be spent, who will have access to resources, monitoring potential safety such as driving cessation, and who will decide upon medical care and have access to the medical records. Section 3 discusses these issues in greater depth.

- Locate a dementia-specific care team involving a social worker, nurse, and other health professionals.
- Make decisions about living wills and advanced directives.
- Plan for driving cessation.
- Establish new routines that are uncomplicated and satisfying.
- Find a mild cognitive impairment or early dementia support group for both the person and family members.
- Enjoy favorite activities, family, and friends while still able.
- Experience the dream activity they have always wanted to do, such as taking a cruise.

The problem with early recognition is that the symptoms are subtle and could be attributed to “stress” or “getting old.” It is only through a rigorous diagnostic evaluation (which may have to be repeated in six months or a year to evaluate for change) that stress or normal aging can be ruled out. To help with

this dilemma, the Alzheimer’s Association has published 10 warning signs that families can use when questioning whether an evaluation is needed. It can be found at www.alz.org as well as below (Table 2).

Table 2. 10 Warning Signs of Dementia

1. Memory loss – problems remembering recent events/information.
2. Difficulty performing tasks – everyday activities such as paying bills, taking medications, performing household chores, etc. become more difficult.
3. Problems with language – forgetting simple words or substituting unusual words on a frequent basis.
4. Disorientation to time and place – forgetting the day of the week or time of day and/or getting lost in familiar places.
5. Poor or decreased judgment – buying unnecessary items from telemarketers, giving away money, or making bad decisions that are inconsistent with past actions.
6. Problems with abstract thinking – more difficulty with complex mental tasks such as planning and organizing, forgetting how to use familiar items such as a computer, etc.
7. Misplacing things – finding missing items or things in unusual places.
8. Changes in mood or behavior – ranging from a depressed/withdrawn mood to becoming more irritable, thus getting upset easily.
9. Changes in personality – becoming confused, dependent, fearful, suspicious, and/or self-absorbed.
10. Loss of initiative – loss of interest in usual activities; maybe sleeping more or watching television throughout the day. ^[2]

Diagnosing Dementia

The diagnostic process consists of answering the following three questions.

1. Is Memory Loss Present?

A diagnosis of dementia is a process that may take several years, especially if the person is early in the disease. Some types of dementia change over a period of several years. This phenomenon is especially true in FTD. It is fairly common for someone to be diagnosed with AD one year, and then receive a diagnosis of another type of disease such as FTD several years later. The reason for this dilemma is that it takes several years for some of the key symptoms to be revealed. This issue can have a significant impact on the diagnostic opinion when the medical staff is frequently changing. Therefore, the family should be sure to report changes seen over time.

The diagnosis of AD is a process of elimination where all other diseases are gradually excluded. A critical factor in making an accurate diagnosis is determining a pattern of symptoms, including how they started and progressed over time. This concern means that a thorough history from a source other than the affected individual is vital. **When seeking a diagnosis, the person with memory loss MUST be accompanied by a family or friend who can assist in providing an accurate history.** People with memory loss can be unaware of their limitations and how it affects their ability to function. This situation makes the history they provide incomplete or incorrect. At Barrow, a family

member will complete a detailed medical and social history, which allows the physician to be aware of any special concerns and unusual or important symptoms. The medical history allows for the physician to consider current and past medical and/or psychiatric conditions or medications that may cause problems with memory and thinking. A social history considers years of education, occupation, daily activities, family role, and functions, etc. The subtle and notable changes in daily living and function are detailed by both the person with memory loss and the family. Any changes in behavior are also explored in detail.

2. What Could Be Causing the Memory Loss and Other Changes?

A physical and neurological examination will take place along with a cognitive on-screen or pen and paper test that evaluates the different types of memory (Table 3). In most cases, additional, more in-depth cognitive tests called “neuropsychological testing” will be ordered for a later date. This set of tests take several hours and helps the physician determine specific areas of the brain affected by the dementing illness, what might be causing the symptoms, and the severity of the disease. Neuropsychological testing looks for patterns of strengths and weaknesses in a person’s thought process. These patterns vary depending on the type of dementia. The testing can also help guide treatment by using the person’s strengths and reducing potential safety issues through an understanding of the person’s areas of cognitive weakness.

Analysis of the blood assesses the overall health with attention to the thyroid, blood, and nutritional deficiencies. Low levels of thyroid function, anemia, vitamin B12 deficiency, high blood sugar, and altered liver and kidney function can all contribute to mental status changes. In most cases these tests are normal. It is important to remember that normal blood tests are not an indication that the memory status is normal.



More examples of normal tests are brain imaging using magnetic resonance imaging (MRI) or a computed tomography (CT) scan. They are used to rule out the presence of a stroke, tumor, or fluid. These scans do not identify the changes that cause memory loss specifically because those changes can only be seen with a microscope. The scans can identify atrophy (shrinkage) to general areas of the brain; however, the amount of brain loss generally does not predict the severity of the symptoms. A positron emission tomography (PET) scan measures the amount of sugar being metabolized (used) by the brain. A PET scan is particularly helpful in diagnosing dementing illnesses that are subtle and do not involve memory, for example, FTD.

In the past, patients and professionals report being taught that it was impossible to diagnose AD because neurologists do not do brain biopsies; only a postmortem biopsy would do. Brain biopsies on living patients are invasive surgical procedures, placing patients at risk. The idea that dementia cannot be diagnosed before death is no longer valid. Using traditional diagnostic techniques and comparing them with postmortem studies, physicians were able to diagnose AD correctly about 97% of the time. With newer methods, the efficacy of the diagnostic evaluation is increasing. Thus, the likelihood of receiving the correct diagnosis is very good. Some types of dementia, especially FTD, take longer to reach a stage where the symptoms are obvious, and patients score quite well on memory-based tests, such as the Montreal Cognitive Assessment. Genetic testing is typically not used in the diagnosis of AD.

Table 3. Elements of the Dementia Work-up

Clinical history
Labs (bloodwork, cerebrospinal fluid testing, urinalysis)
Cognitive testing (cognitive screening test and/or neuropsychological testing)
Neuroimaging (MRI, CT, PET, DAT)
Physical and neurological exam

3. Are the Symptoms and Findings Consistent with What We Know About a Particular Dementia?

Once the physical exam, lab, and imaging results are completed and reviewed, the physician will make a more specific working diagnosis. For a diagnosis of AD, all of the test results will be within normal limits, except the neuropsychological tests. The symptoms will stem from the loss of memory. A treatment plan will be identified to address symptoms and assist with everyday living.

This plan should include a discussion of available medications, lifestyle and environmental modifications, caregiver and patient support, and available clinical research trial options. It should also include a review of the patient's medication list and elimination or reduction of potentially problematic medications, such as those found on the "Beers List" (see Resources).

Treating Dementia

Medications

There are no medications at this time to stop or reverse the symptoms of memory loss in AD. If a patient with a diagnosis of AD has no heart irregularities, they may be placed on medication(s) with the goal

of stabilizing or slowing the rate of cognitive decline. People with vascular dementia and DLB may also receive medications used to treat AD. They will be monitored to evaluate the effectiveness and possible side effects. The patient and their family will benefit by meeting with a social worker or a community health educator at Barrow to discuss daily living concerns and how to identify and obtain necessary community services. The Alzheimer's Association or local Area Agency on Aging may also be useful sources of help and support (see resources listed in Section Five).

People with neurodegenerative cognitive disorders become increasingly sensitive to medications given for their effects on the central nervous system (brain and spinal cord). The higher probability of adverse effects to medications must be monitored by families (where drugs are administered) and by the prescribers. All medications should be prescribed at the lowest possible dose and increased slowly over a period of weeks. Care must also be taken to evaluate any over-the-counter medications and nutritional supplements the person takes in addition to other prescriptions they take, as there may be serious drug-drug or drug-food interactions. It is very helpful to consult with the pharmacist on all medications and supplements when a new drug is added.

It is important to take care with medications that affect the central nervous system because they can cause drowsiness, leading to falls. Falls can result in broken bones and bleeding in the brain. In certain cases, these medications can also lead to a condition where the person is unable to stop an activity such as yelling, overeating, spending money, or noisy behavior.

• Types of Medications for Dementing Illness

Cognitive Enhancers

The name of this group of commonly prescribed medications is a bit deceiving. They are helpful in treating memory and thinking problems by slowing the progression of symptoms and, in some cases, improving the clarity of thought. They may also help with managing behavioral symptoms. However, none of the current treatments for dementia radically improves patient memory or thinking, nor do treatments stop the progression of the disease. They may help to slow the progression, which makes early diagnosis and implementation of this treatment imperative.

The cholinesterase inhibitors are a group of cognitive enhancers developed for use in AD. The first name is the generic name followed by the "also known as" (aka) trade name: donepezil (aka, Aricept), rivastigmine (aka, Exelon), and razadyne (aka, Galantamine).

Memantine (aka, Namenda) is used to treat moderate to severe confusion (dementia) related to AD. This medication works by blocking the action of a natural substance in the brain (glutamate) that is believed to be linked to symptoms of AD. Namenda may help moderate to severe dementia, while Aricept, Razadyne, and Exelon may help patients in earlier stages of dementia.

Some side effects may occur as the body adjusts to the drug. They may include nausea, vomiting, diarrhea, loss of appetite, weight loss, dizziness, drowsiness, weakness, trouble sleeping, shakiness (tremor), or muscle cramps. If side effects occur, they usually last one to three weeks and then lessen.

Antidepressants

Depression and anxiety are common complications of several types of dementia. Antidepressant medications, especially the SSRI-type, can be very helpful in controlling depressive symptoms, anxiety, irritability, impulsivity, and hypersexuality, especially when combined with “environmental interventions” (Section Four).

Anxiolytics

Anxiety is common in dementia, especially as the disease progresses. Part of this problem is because perception, the brain’s ability to interpret sensory information (visual, tactile, auditory, smell, and taste) from the environment, is altered. The result is that what was familiar is now unfamiliar. The person begins to withdraw and exhibits anxiety and fear.

Most people with dementia have at least some insight into their condition and are fearful of being abandoned in a nursing home. This fear results in a refusal to accept any change or new experience, such as adult day programming. Initially, fear is often dealt with by addressing the issue verbally rather than by trying to treat it with medication.

In the past, anxiolytics (benzodiazepines) were used for anxiety. Barrow does not recommend these drugs because experience with an elderly population has shown that these drugs can cause sleepiness, instability, falls, increased confusion, and agitation. If your loved one is being prescribed these types of drugs, we recommend asking your provider about using an SSRI-type antidepressant.

Medications for Sleep

Many medications for sleep are not advisable in dementia because they may cause increased confusion or agitation. These include medications like diphenhydramine (aka, Benadryl) and most over-the-counter sleep aids that contain it, benzodiazepines (e.g., lorazepam, alprazolam), eszopiclone (aka, Lunesta), and zolpidem (aka, Ambien).

Better alternatives to discuss with your doctor include trazodone or mirtazapine, which are sedating antidepressants with a better side-effect profile.

Atypical Antipsychotics

When someone with a dementing illness has severe agitation or aggression, most doctors will start the person on medication. Doctors may start by prescribing an antidepressant, but if it fails or the aggression is posing a danger, an atypical antipsychotic may be prescribed. Individuals receiving these medications should be closely monitored by their doctor. This class of medications carries a “Black Box Warning” from the FDA because they can increase the risk of heart attack or sudden death. However, these medications can be highly effective when used properly.

Antipsychotics are prescribed using their side-effect profile – meaning doctors use the drug with the least side effects at the lowest possible dose for the shortest time possible. While the antipsychotics are being used, efforts should be made to calm the household, start activity programs, and rid the environment of things or people who are disruptive. An example of a disruptive environment might

include a family moving the person with dementia in with a family of four young children. A second example is a noisy dining room in a long-term care facility. Noise, boisterous people, too many choices, and fatigue can make life miserable for someone with dementia, as their brain has difficulty processing multiple stimuli at once. The next section focuses on how to identify problems in the environment and plan for changes that prevent troublesome behaviors.

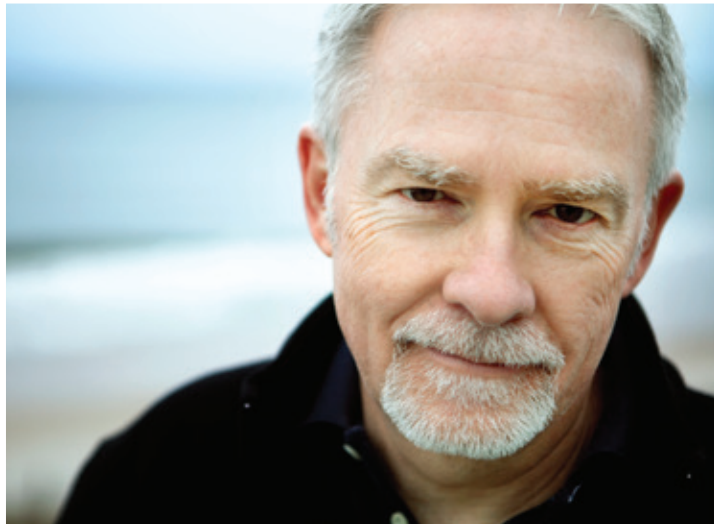
• Clinical Studies and Research

Clinical studies, sometimes referred to as clinical trials, are research studies conducted in people to determine whether treatments are safe and effective. Without clinical research and the help of human volunteers, there can be no better treatments, no prevention, and no cure for AD.

Barrow conducts clinical studies for various dementias, to better understand how they develop and progress, find better ways to diagnose them early, and identify new and better treatments and ultimately a cure for these disorders. These studies include:

- **Treatment trials** to test new treatments or combinations of treatments to slow or stop the disease or reduce symptoms associated with the disease (e.g., agitation or psychosis).
- **Diagnostic studies** that find new tests or procedures for diagnosing the disease.
- **Prevention trials** that investigate ways to prevent the onset of the disease.
- **Quality-of-life studies** that explore ways to improve the quality of life for individuals who have a chronic illness, their caregivers, and their family members.

Although many individuals affected by dementia seek out clinical studies in an effort to find new and more aggressive treatments, it is important to understand that even if you are not interested in trials involving experimental medications, you can make an impact on our knowledge of this disease. Studies of neuroimaging techniques, annual pen-and-paper cognitive testing, or studies analyzing blood and other bodily fluids may require as little as one visit a year. They can have a huge impact on our understanding of the disease and can help in the development of better treatments in the future. Healthy individuals, such as care partners or family member, can also participate in many of these types of studies.



The more scientists know about dementia-related changes in the brain, the greater the chance of finding a treatment that prevents or reverses these changes. You can also help advance dementia research by volunteering for a clinical trial. If you are interested in learning more, please call Barrow at **(800) 392-2222**.

Common Dementing Illnesses: The Basics of Care

Amnesic Mild Cognitive Impairment

MCI is a term used to describe subtle but notable changes in language, attention, reasoning, judgment, reading, and writing. The most common complaints noted are memory problems. Most people with amnesic MCI are aware of their symptoms and may express fears of losing capacity, suffering, and facing stigma. It is important for the person to discuss their illness with non-judgmental professionals, often a nurse or social worker, who can reassure them that Barrow will guide them as long as necessary.

People with MCI carry out everyday activities without difficulty; therefore, they do not meet the criteria for having dementia. Every type of dementia goes through an MCI stage, though not everyone with MCI will go on to develop dementia. The most common type of MCI is called “amnesic MCI” because it involves memory changes. This type of MCI typically progresses to Alzheimer’s dementia. Currently, there is no approved treatment, but it is recommended to treat other health problems such as diabetes, high blood pressure, and depression. Managing these problems can often improve mental functioning. There is also mounting evidence that medications used to treat dementia, as well as lifestyle modifications made at this early stage of illness, can be helpful in slowing the progression of MCI to dementia.

Alzheimer’s Disease

- **Early Stages**

AD is the most common form of dementia, accounting for approximately 60% of all dementias. It is typically characterized by the gradual onset of memory loss followed by a slow continued decline in other areas of mental, and eventually physical, functioning. Life expectancy with AD varies for each person. The average life expectancy after diagnosis is eight to 10 years. However, it can be as short as three years or as long as 20 years.^[2]

AD can strike at almost any age; however, “young onset” usually means the person is in his or her 40s or 50s. The prevalence increases with age; by age 65, about 10-15% of the population has dementia; by age 75, about 30% of the population has dementia; by age 85, about 50% of the population has dementia.

It is important to remember that the primary disability in AD is a loss of memory, usually starting with not remembering recent events. Common losses begin with difficulty in managing complex activities and tasks. This may include difficulty with managing finances, using computers, entertaining, and performing at work. Worsening gradually over a period of years, early AD affects social interactions, serving on committees, and making plans, such as vacations.

As a general rule, people are aware of their losses in early AD. It is common that they develop depression, which is treated with antidepressants; this treatment is important because untreated depression can make the symptoms of dementia worse.

Driving abilities decline early in the disease because of changes in visual and spatial awareness. The person’s depth perception declines as does the ability to perceive objects that are moving. The person may complain of visual changes, yet they are not identified during an optical evaluation. What is happening is “the eyes take the picture, but the brain doesn’t develop the film correctly,” resulting in getting lost and making judgment errors while driving.

As the disease progresses, everyday activities such as shopping, doing laundry, cleaning, and cooking are affected. Short-term memory continues to decline, as does the person's developmental level. The person becomes more self-centered and has impaired reasoning ability. Their sense of time diminishes, which often produces anxiety about when activities and appointments should occur, and the person might arrive hours before scheduled events.

Toward the end of the early stage, driving becomes noticeably impaired, and measures are taken for driving cessation. The person has fender benders and may become lost in previously familiar settings. He or she may begin to receive traffic citations, and adult children may make rules about whether their children can be in the car when the person is driving.

- **Moderate Stages**

The moderate stage of AD starts with changes in abilities for self-care. The first function lost is generally bathing. Recognizing the difficulty of sequencing the steps of complex activities such as showering, the person may refuse to bathe or skip steps such as adjusting water temperature or using soap. Unable to perceive depth, the person may be justifiably concerned about falling or may fear water splashing onto their head. These fears are realistic and disabling. The person is aware of the limitation and is often frightened, but the more he or she tries to meet the goal, the more difficult it becomes.

People with AD will often develop excuses for not bathing, angering caregiving family members who feel the person is becoming manipulative. On a day without stress, the person will be able to complete the bath, yet when stressed is unable to function. Then after a period of being unable to bathe, the person may be able to function again. Inconsistent task performance leads to angry care partners and family who may believe the person is faking their disability. Family members may try to retrain the person. "Retraining" can help while the family is present and coaching; however, after the family leaves, the person quickly forgets what they "learned." This level of disability indicates the person should no longer be living alone. Appendix 1 is a questionnaire developed to help families and professionals determine whether the person is safe to reside on their own.

Over the next few years, the disabilities progress predictably. Problems with bathing are followed by grooming, then selecting clothing. The person may select the same clothing day after day. These disabilities occur because there is an inability to cope with even small changes. Changing to a different type or color outfit might produce agitation.

After this change occurs, dressing becomes a problem. Dressing is a complicated task for which you have to know what each piece of clothing is, where it goes on the body, and the sequence of putting on the clothing. In addition, things must be right-side out, and fasteners applied correctly. When this challenge happens, families are encouraged to have the person wear the same color and style of clothing each day. Not only does that help the person to dress but is very helpful in locating the person if he or she wanders outside. About 60% of people living at home with moderate stage dementia will wander away from home at least once, compared to 20% of residents with dementia residing in long-term care. If the person wanders away, you need to have a recent picture to give first responders, and it is helpful if the person is wearing the clothing in the picture.

Communication abilities are lost over time. This loss, plus changes in sensory abilities, may tend to make social activities or outings difficult for the person. The sensory changes may lead to quick fatigue and requests or demands to return home.

Late in the moderate stage, people develop challenges with walking and with bladder and bowel control. These disabilities serve to limit what families can manage in the home and often result in a move to residential long-term care placement.

Behaviors in Moderate Stages

In the moderate stage of dementia, a significant proportion of people with AD develop “non-cognitive behavioral symptoms.” Diseases that cause memory loss, including AD, Parkinson disease, and strokes, have a variety of symptoms that can baffle and overwhelm family members. Some of the most challenging and frightening problems rarely occur early in the disease but may “pop up” when it is least expected as the disease progresses. Examples include the following:

- Becoming anxious, agitated, or aggressive at a particular time of the day
- Withdrawing and sitting alone when guests are present
- Suddenly driving aggressively
- Demanding to leave during an activity or event they had been anticipating
- Waking up in the middle of the night to get dressed to start the day
- Not recognizing familiar settings, home, or family late in the afternoon or at night
- Accusing family members of stealing items that the person has hidden or blaming “outsiders” for taking things
- Threatening family members with physical violence
- Becoming irritated or belligerent late in the day
- Refusing to bathe, go to the doctor, or go out socially for no apparent reason
- Walking away from home or getting lost
- Telling stories that they know aren't true
- Thinking there are extra people or children in their home
- Seeming selfish, denying their needs or those of family members



These behaviors may seem mean-spirited and purposeful, but they are simply symptoms of the person's brain disease. **These behaviors are normal and expected in the mid-stage of AD. It is important to realize that the person cannot control these sudden behavior changes, nor can they follow your directions to stop the behavior, but you can help to prevent or minimize the behavior.**

Although not everything works all the time, we can eliminate much of the “acting out” behavior by making simple changes in our behavior and the environment. The changes help the person to succeed. Unexpected changes in behavior are often triggered by things you can control, once you know how. The purpose of this booklet is to teach you what triggers those unexpected problem behaviors and how to change the person's routine to prevent them.

First, it is important to understand that these behaviors are not about you. The behaviors you are noticing are about the person's decreased ability to tolerate stress and stimuli, such as group participation, fatigue, changes in routine, and loud noises. These stressors collect throughout the day until the person has the equivalent of a panic attack. These attacks are called “catastrophic events,” and we treat the person experiencing them as we would a panic attack:

- Stop the activity immediately when in a safe location.
- Give the person a time out.
- Acknowledge the person's discomfort and your intention to help.
- Agree that they are frightened and uncomfortable and **APOLOGIZE. While you are not at fault for the behavior, apologizing helps to put the person at ease.**
- Express empathy and compassion: *“I'm so sorry the doctor wrote the Motor Vehicle Department (MVD), and they took your license! That stinks!”*
- If the person is angry about something that they think needs fixing, vow to fix it when you have time. *“I'm too busy to call the MVD today, but I will call them for you as soon as I get a free minute tomorrow.”* While you won't “have time” to contact the MVD, it allows the person to relax knowing their needs will be met.
- A good example of this situation is the person who wants to drive, despite being told it is unsafe. If you argue about the demand not to drive, the agitation will escalate. If you say, *“I'll look into that tomorrow when we have more time,”* it delays the confrontation and gives time for the person to forget. We call this response a “therapeutic fiblet” because the fib can save the person and care partner hours of agitation and anger.
- It is important to understand that at this point in the illness, the person's “reasoner” is broken.
- Have a time out after the episode with the television off.
- Keep a journal of the day and time of the behavior. Describe what happened and, if you can, what caused it. Note how you managed it and how well that worked. As your journal develops, you will be able to see patterns, and you will become more skilled at managing.

What Triggers and Prevents Problem Behaviors and How to Manage Them

Fatigue

People with dementia tire very easily. This tiresomeness is, in part, because they have to concentrate so hard all the time. Late-day or evening confusion and waking at night are often

referred to as “sundown syndrome” because early clinicians thought it occurred due to changing light levels. Research has shown that the cause is fatigue, as it is prevented by having regular rest periods and relieved by giving a rest period. Try the following suggestions to prevent fatigue:

- ♦ **Give the person a rest both in the morning and the afternoon.** This rest may be just a quiet period or an actual nap. If the person naps, have him/her sleep in an easy chair or the sofa, so they know when they wake up that the rest period was a nap, and that it is not morning all over again!
- ♦ If the person is going to bed early, have them sit quietly in an easy chair just before supper. This rest will help the person stay up later and not waken late at night.
- ♦ **If the person is waking at night, DO NOT keep them up all day.** Forcing them to stay up all day will make the night waking worse! Instead, let the person sleep mid-morning, after lunch, and before supper for about an hour each time. Have activities during times when the person is awake. Assist them with exercise (e.g., walking, dancing, vacuuming, chores, sweeping).
- ♦ Avoid foods and beverages with caffeine. Try coffees, teas, colas, and pops without caffeine.
- ♦ If you are planning a social activity or trip, make sure the person is well rested both before and after the trip. Many families make the mistake of trying to accomplish too much during the day. Travel for a while, then stop and rest.
- ♦ **Get to know the person’s “best time of day.”** Use that time to visit friends, go to the doctor or dentist, or travel.
- ♦ **Plan activities that are of a shorter duration.** Ninety minutes or less has been identified by researchers as the optimal time that any activity should end. Instead of cleaning the house in a single day, spread the chores across several days to prevent the person from becoming overtired.
- ♦ During holiday gatherings or special occasions such as weddings or reunions, when the person is away from home, plan in advance a place and times when he or she can get away to rest during the activity.
- ♦ Many persons go through a period where they sleep a great deal. If this situation happens, check for depression or boredom. If neither is present and the person is still sleeping at night, understand it is normal for the illness. This time is a valuable break for you, the care partner, to get things done, catch up on your rest, or indulge your own interests.

Changes in Environment, Routine, or Caregiver

People with memory loss have problems with planning and sequencing the steps of an activity in order to reach a goal. **The more they think about an activity, the less they are able to do it even though they could do it yesterday or can tell you how to do it!** Help the person and decrease their frustration by doing the following:

- ♦ **Have a routine you follow during the day.** While the timing of the routine is not critical, **the sequence of activities is very important.** For example, if the person gets out of bed, has breakfast, and then bathes and dresses, it is not a good idea to have them get out of bed, bathe, dress, and then eat breakfast. This change produces frustration and anxiety that can accumulate throughout the day and produce increasing problems in the late afternoon or at night.
- ♦ When well-meaning family and friends suggest the person needs a change of pace, gently reassure them that change may not be in the person’s best interest.

- ♦ **Redecorating the house, decorating for the holidays, moving, or even rearranging the furniture can produce problems.** Before moving, redecorating, or remodeling, consult with your memory loss specialist (either the nurse or social worker). Seeking advice in the beginning can save many problems later.
- ♦ Keep holiday decorations simple and short. Avoid having many long holiday gatherings and parties with large numbers of guests. Simple, quiet festivities are enjoyed more by the person and are less likely to result in behavior problems.
- ♦ If the person demands to be taken home during a party or becomes rude to friends or children, understand this behavior is not aimed at the person. It is simply the person's way of telling you he or she is tired or overwhelmed by the activity level and/or changes. **Use the demand to leave as an indication that it is time to go home. Do not try to convince the person to stay for even a few extra minutes as it can precipitate waking at night confused or wandering.**
- ♦ Travel can be especially difficult. Plan trips with the help of a knowledgeable professional who regularly helps families manage problems associated with AD and related disorders and travel. **Keep travel as simple and brief as possible. Prepare for problems by having your loved one wear an identification bracelet, helping the person through security screening, using services for the disabled, etc. People with dementia should never, ever travel alone!**
- ♦ Occasionally you will plan trips or events that you know will trigger increased confusion. Expect the confusion. **Plan to have extra help or medications on hand** to see you through this period.



Overwhelming or Misleading Stimuli

People with memory problems suffer the loss of ability to properly interpret what they see and hear. **Noises and what they see often become distorted**, like a funhouse on the midway at the state fair. This inability causes the person to become uncomfortable in crowds or in noisy settings. Groups as small as 10 people can result in an angry outburst, a demand to leave, or rude statements, especially if the person is tired.

- ♦ **If the person wants to leave a restaurant, store, or gathering, it is a good idea to honor their wishes and leave the setting or have them retire to rest for a while.**
- ♦ Encouraging the person to continue to attend or stay at a social gathering may produce severe agitation or waking up confused that night or up to 36 hours later.
- ♦ Use the person's requests to leave as an indication of how much activity, noise, and how large a group the person is able to tolerate.
- ♦ **If the person begins to complain of people at home who aren't there, for example, seeing little people or children, turn off the television, take down family pictures,** and cover windows at night. Mirrors may have to be covered with roller shades, especially in the bathroom. The person may not recognize their reflection and leave thinking a stranger is in the room. It is best to call the Barrow memory loss specialist and talk this situation over with them.
- ♦ If the person begins to develop ideas that people are in the house, becomes suspicious that people are doing things behind his or her back, or tell stories you know aren't true, **don't argue or correct them.** Recognize that the person's brain is not processing correctly. **The illusions and beliefs, which are very real to them, are often misinterpreted stimuli. The most common cause of delusions (fixed false beliefs), hallucinations, illusions, and confabulation (reporting false stories as truth) is the television.** Watch television as little as possible, avoiding shows that involve violence, arguing, or other disagreeable content. The person believes these ideas. Correcting the person will simply convince them that you don't know or care about what they are experiencing. It is best to **reassure the person of the following:**
 1. **They are safe.**
 2. **You have taken care of the problem, or you intend to take care of it. (Although the response is a statement, you do not necessarily act on it.)**
 3. **You understand the person is concerned and upset by what they are seeing or hearing.**

Another source of illusions comes in advanced dementia, when people are often "visited" in dreams or when awake by deceased relatives or friends. Ask the person who is insisting they "see" dead relatives whether the visits are frightening or pleasant. If they are frightening, medication may help. If they are pleasant, encourage the person to talk about them. **Do not try to convince the person that the relatives are dead.**

Loss of Meaningful Activities

Activities define who we are. When the person loses the ability to drive, work, mow the grass, cook, or perform other meaningful tasks, depression or anxiety may result. It is important to substitute old cherished activities with similar simpler activities. One important thing to remember is that the person is regressing developmentally as the disease progresses. This regression affects reasoning, judgment, and responses to losses of cherished activities.

- ◆ Probably the best sources of activities are adult day programs, although there are now “Dementia Friendly Communities” (such as Tempe and Mesa, AZ) where people with dementia and their families can develop friendships and participate in activities on a regular basis.
- ◆ **If you have adult day programming available, use it.** It can provide social contact and meaningful activities for the person as well as respite for you. Introduce the person to the program slowly and stay with them on the first day or until they get used to the staff. Research suggests that people who attend adult day programs adjust more quickly when residential long-term care placement is needed.
- ◆ If there is a recreational or occupational therapist in your area, talk with them to help design replacement activities. If no therapists are available in your area, contact a nursing home, and ask for the activity director.
- ◆ Allow the person time to talk about their losses. Grieving is normal, even desirable. If the grieving lasts for more than three weeks or affects sleep or appetite, see the person’s primary doctor about treating the person’s depression.
- ◆ Discuss the disease process with the person so he or she can understand why activities are being lost, and you do not think “they are going crazy.” If the person is losing driving privileges, either you or a health professional should tell them the reason. If no one discusses the problem with the person, they are likely to develop paranoid or suspicious ideas. While you may not choose to use the term “Alzheimer’s disease,” most persons can understand the idea of “brain disease” or “memory loss problem.”
- ◆ The person may become angry or deny their memory loss. If the person gets angry, drop the subject for a time. Apologize for bringing it up. The goal is not to get the person to admit the memory loss but to help them to understand why these things are happening. Denial and anger are a normal part of the grieving process.
- ◆ Do not assume that ignorance of the disease process leads to a happier person. Also, do not think that telling the person about the memory loss will “kill them” or cause them to “give up.” This situation is very rarely the case. Trying to hide the illness from the person becomes increasingly difficult and strains your relationship with the person.
- ◆ Have the person help around the house. Many people can manage simple activities such as dusting, sweeping, table setting, sorting, and helping with simple cooking tasks late into the disease. Think of the activities as therapy. **Do not evaluate the results.** If the person’s performance is incomplete or sloppy, accept it is part of the disease process and recognize that the activity remains valuable for your loved one.
- ◆ Look at activities that may be too dangerous such as using power tools, hunting, feeding livestock, or working with flammable tools, and try to replace them with safer activities. Many men & women who have not had hobbies are able to learn simple repetitive tasks with supervision, such as painting, latch-hook rug making, cooking, and simple woodworking.
- ◆ Pets, gardening, and musical activities often produce a high degree of satisfaction and offer good exercise.
- ◆ Exercising three times each week helps to maintain a positive mood and functional abilities. Exercise may include walking, gardening, dancing, or the use of a stationary bicycle.
- ◆ Reading aloud to your loved one is often a satisfying and reassuring activity even late in the disease.

- ♦ In late-moderate dementia, television and films are the most common cause of hallucinations and delusions. The person is unable to determine what is real versus drama. Do not use television as a babysitter. If the person is watching television all day, you might want to find an adult day program or hire a companion to participate in activities. Use videotapes to your advantage. Obtain videos of old television comedies, tape favorite sporting events, and have videos of family members. Avoid stories that include violence, murders, or cartoons.

Creating Too Much Demand

- ♦ Many care partners feel they need to exercise the person's brain, test them every day, and push them to achieve. It is unnerving for family members to hear the person make mistakes and not correct them, but it is essential to refrain from creating too much demand on your loved one.

Think about how you feel when someone tells you you've made a mistake. Being corrected feels bad. The person with memory loss is constantly confronted with their mistakes, which is pretty uncomfortable. What we try to do is make the person feel comfortable with the knowledge they have, as long as they are safe.

- ♦ Avoid trying to exercise the person's brain. The brain is not a muscle. People with memory loss are not lazy; they have a disability that is, in many ways, like an amputation. We have to assume they are working as hard as they can at any given moment with the abilities they have left at that time. People with memory loss have good days and bad days. Accept the person's changing abilities each day or hour as the best the person can do at the time.

- ♦ **Avoid quizzing the person: "Do you remember me?" "What is her name?" "Remember what we did yesterday?"** Life becomes like a constant test for people with memory loss, and we don't want them to feel as if they have failed that test again and again.

- ♦ If the person becomes upset, try to distract them rather than confronting them. If that does not work and the person is safe, walk away and let them forget.



- ♦ Research suggests that humans tend to forget good experiences and remember the bad ones. Try attaching memories, such as the day the car was sold, to happier activities such as going on a hike or out for ice cream. Your person will be less likely to remember that the car is gone.
- ♦ Another trick is to fib that your doctor wants you to practice driving for when the person in your care is no longer able to drive.
- ♦ **Do not announce things in advance.** People with memory loss have problems figuring out time. They become upset and fearful about schedules, especially doctor visits. Announce activities at the last possible moment.

- ♦ **Let the person forget.** If you lose your temper when the person refuses to bathe, or there is a behavioral outburst, leave the person alone and approach them again later. The outburst will probably have been forgotten.
- ♦ **If the person has forgotten how to do an activity, help them with it.** Don't try to "talk them through it," or have them "think about it." Thinking about it only worsens the problem. Use distraction instead. Distraction is simply changing the subject. Examples include moving on to another task, giving the person a glass of juice or water, making a phone call to a friend, looking at family pictures in an album, or reading a letter aloud. Let the memory loss work for you. If a letter, joke, or other distracter is helpful once, don't be afraid to use it again and again.
- ♦ **Sometimes your loved one's forgetting can actually be useful. If they become upset about something, reassure them and don't bring it up again.**
- ♦ Whenever possible, **give the person a choice.** *"Do you want a bath or a shower?" "Would you like a person to stay with you in the home or to enroll in an adult day program?"* Realize that we **avoid the term, "Do you want to...?"** The person with memory loss will tend to answer, *"No!"*
- ♦ Try to end discussions of "hot button" topics on a positive note. People with dementia tend to remember things associated with negative emotions, *"You must never drive again!"* is remembered far longer than, *"The car is broken, and the shop will call us when the part comes in."* This last response is a therapeutic fiblet that helps avoid a negative situation.
- ♦ Choose your battles carefully because battles increase agitation and tend to be remembered. Ask yourself, "Is this battle the one to die on the beach for?"

Illness

If the person is not feeling well, has pain, is coming down with a cold, has a medication reaction, or has an infection, you will probably see a sudden onset of problem behaviors and confusion that does not go away with rest. If this situation happens and the person does not improve within one hour, complains of pain, has shortness of breath, is bleeding, or is vomiting, you need to take the person to see the doctor as soon as possible. Think about the following common problems:

- ♦ Has the person been drinking at least one and a half quarts of liquid each day? Are they urinating frequently? Does their urine smell strong? Urinary tract infections are very common causes of agitation.
- ♦ Does the person have arthritis or another painful condition? Is the person on his or her feet all day? Does the person "hold" or protect a part of his body? Even though the person may not complain of pain, we need to think about it. Ask the doctor for a medication you can use to relieve pain, and use it regularly for **mild** pain. If the pain is allowed to become severe, the pain medication will be ineffective. **If the person begins to moan, yell, or scream, suspect he or she might be in pain.**
- ♦ Be concerned about constipation. Make sure the person receives adequate fiber and fluid in their diet, but avoid laxatives and enemas.
- ♦ Have the person's prescriptions, over-the-counter medications, vitamins, and herbal preparations checked regularly by your doctor or pharmacist.
- ♦ **Avoid alcohol** intake as it can worsen memory permanently. Many people with memory loss over-react to alcohol. Try alcohol-free beers, wines, and mixed drinks as a substitute. If the person becomes upset, try mixing more and more diluted drinks. Some care partners add water to liquor

bottles after their loved one goes to bed. Ask your physician to tell your person not to drink alcohol.

- ◆ Talk to the person's physician about their health and preventing illness. You may want to ask about flu shots, the vaccination for pneumonia, and the vaccine for shingles. Make sure tetanus immunizations are up to date.
- ◆ Diet and nutrition may become a problem. Have your person take a simple multivitamin daily, especially if they are not eating a balanced diet. Become concerned if the person begins to lose more weight than six pounds in six months. Unless the person is on a weight reduction diet, weight loss greater than six pounds in six months is cause for alarm no matter how heavy they were before. Schedule a medical appointment. Consult with a dietitian. If the person refuses to eat, try different foods that are high in calories. Instant breakfast drink in whole milk can be used as an inexpensive, tasty, and fully effective nutritional supplement.

• **Advanced Stages**

Over time, as the disease continues to progress, the brain loses neurons and shrinks in size.

The person will have severe loss of both long- and short-term memory. The person with AD loses communication abilities for both spoken and written language but can often respond to non-verbal cues, including body language and emotion. There is a decline in purposeful movement, especially walking. The person's walking advances from shuffling to needing assistance.

Dependent in all activities of daily living, the person requires 24-hour care for every aspect of daily life. Despite these overwhelming losses, people with advanced dementia still may be able to communicate in a few words. Many people have "windows of lucidity" where they are more alert, and they can communicate a few words or sentences that are appropriate to the conversation. The person may still be able to respond to a favorite food, spiritual activities, and being in the presence of those they love.

Some people with advanced dementia report seeing friends and family who have passed on. Others report spiritual experiences such as meeting deities or being given directions that can be very satisfying.

Advanced AD occurs when the person can no longer walk by themselves. Falls are expected as the person may try to walk or use a walking device on their own. Falls tend to be more severe as people often tumble backward or climb over bed side rails. Slipping on excrement is common. The person lacks the time and perception to respond to protect themselves from injury.

The person becomes incontinent, as he or she no longer responds to the natural signals to evacuate the bowel and bladder. Chewing and swallowing must be monitored because aspiration (breathing saliva into the lungs) and choking can result.

Weight loss is common, although there are "dementia-friendly" foods that are soft, sweet, and are given adequate time to eat. These foods can prevent weight loss. Dehydration can result if the person is not given small amounts of fluid throughout the day. The person may become bedbound and thereby suffer skin breakdown that occurs very quickly. Pain can result from unused joints if the person is not repositioned every hour or so. People with advanced dementia sleep about 20 hours per day. They express unmet needs such as hunger, pain, and boredom with restlessness, agitation, and spontaneous vocalizations.

Loss of developmental skills and the return of primary reflexes are common. These reflexes include the return of the suck reflex, primitive grasp, and startle reflexes. These actions, particularly the grasp, can be misinterpreted as aggressive behavior. Care providers should be reminded to wear long sleeves to protect from being scratched or bruised while providing care.

At this point in AD, the person does not consistently recognize family members and has very limited ability to communicate. There is a return of the primitive reflexes seen in infancy.

In the advanced stage, the person has developed urinary and fecal incontinence (lack of bladder or bowel control). As time passes, the person is totally dependent on caregivers for activities of daily living. The person must be fed and begins to have difficulty swallowing. The person can become immobile and develop pressure ulcers and repeated infections.



Medicare covers hospice care for people with dementia; however, because of the uncertainty about the length of the illness, the criteria for admission are strict. Death in AD is usually due to pneumonia from aspiration (breathing in) saliva.

By the advanced stage, people with AD and related dementia usually have lost the ability to communicate in a meaningful way, walk independently, control bladder and bowel function, and care for themselves. At this stage, hospice care can be very beneficial for both the person with dementia and their family. Typically, the cause of death in all types of dementia is an infection, such as pneumonia.

Although people in their 40s and 50s can get AD, the greatest risk factor for AD is older age. At age 85, roughly half of the population has AD. Life expectancy is eight to 10 years once the person is diagnosed.

Engaging Hospice Services

Hospice care is a covered Medicare benefit. It can maximize the quality of life and comfort for the person with dementia and the care partners during and following the illness through bereavement care. Hospices use a team of experts in end-of-life care to support the family or institutional caregivers. Hospices tend to use principles of palliative care, meaning the person is kept comfortable, but “heroic,” acute, or aggressive care is not used.

If the family decides they prefer “curative” or acute care, the person would be discharged from hospice and returned to the pre-hospice program of medical treatment and care. This situation is fairly typical as families are often conflicted in their understanding of the condition(s) that caused the dementia.

Most hospice centers provide care in either the person’s home or a long-term care, residential institution such as a nursing home, assisted living facility, or group home. Very few hospices have long-term residential beds.

The person must meet the following (or similar) criteria to qualify for admission to hospice:

- Life expectancy of six months or less if the disease runs its natural course
- The person is unable to walk, bathe, and dress independently
- There is no meaningful communication
- One or more of the following has occurred in the past year:
 - Aspiration pneumonia
 - Kidney or urinary tract infection
 - Recurring fever after antibiotics
 - Pressure ulcers (aka, “bed sores”)
 - Weight loss

Family caregivers can access hospice in either of two ways: 1) they can contact their care provider to request an assessment, or 2) they can contact the hospice directly for an assessment. Once approved for admission to hospice, the service is scheduled for six months. If the person has not passed away, he or she must be recertified, meaning there must be evidence that the illness is still progressing. This situation does not mean the person is obligated to die within a certain period; it only indicates they still have the condition that could end their life.

After six months, recertification will be undertaken every three months. To aid in the recertification process, families are strongly encouraged to maintain a journal, recording new complications or health issues. Examples of new progression can include the following:

- Food intolerance with vomiting, diarrhea, or abdominal discomfort
- Calling out, yelling, screaming, or other spontaneous vocalizations
- Sleeping more than 20 hours per day
- Choking
- Refusing food or fluid
- Having “absent” periods where the person is conscious but has spells where they are unresponsive
- The onset of new conditions such as seizures or spontaneous fractures (bones break)
- New onset of violent or aggressive behavior

If the family and care team members jot down the new behavior/symptom on a calendar, it becomes a simple matter to recertify hospice care for another three months.

SECTION TWO— Non-Alzheimer's Dementias

You've gone to lectures or read an article on AD. Your loved one has some of the symptoms, but a number of things don't match. There may be memory loss or not. There may be motor symptoms, such as weakness, or not. The personality might be changing drastically or just a little. Your person may have insight into their condition or not. What could be happening? Families often report feeling like they imagine things because their person's symptoms are not what was described in books or by experts. Sometimes dementia is not caused by AD. In non-Alzheimer's dementias, the symptoms may share some characteristics of AD, but the entire picture just isn't quite the same.



In this section, we discuss the presentation of three of the most common non-AD dementias: dementia with Lewy bodies (DLB), frontotemporal lobar degeneration (FTD), and vascular dementia. This section is a brief overview of the conditions, special care issues, and tips on management. Each of these conditions has specific care needs; however, it is impossible to cover them all in one brief booklet. Suggestions for additional references on the non-AD dementias will be provided at the end of this section.

Why Bother?

If the non-AD dementias look like AD and have no meaningful treatment or cure, why do we bother with advanced diagnostic evaluations and specialized care programs? Simply put, we bother because the care is different than that of AD. Trying to use

interventions designed for AD can result in the person acting out and possible injury to the person or care partner. One example of this issue is that people with DLB are at a much higher risk of a fall than people with other dementias. Thus, the approaches to safety are more focused on fall prevention and safety.

People with non-AD dementias may behave differently than people with AD. They may have symptoms earlier, as early as their 30s. The person with non-AD dementia may have troubling and even dangerous behaviors, lack insight, or exhibit psychotic symptoms, such as hallucinations or delusions. Non-AD dementia symptoms may progress at different rates than AD symptoms. People with non-AD dementias, such as DLB, respond to medications differently and may suffer life-threatening adverse reactions.

Some people with non-AD dementias develop pronounced movement disorders, such as Parkinsonism. Finally, some dementias have genetic links that families might consider if planning to start or add to their family.

In dementing illnesses, the presentation of symptoms is primarily determined by the location of the damage in the brain. Figure 3 shows the regions of the brain and their functions:

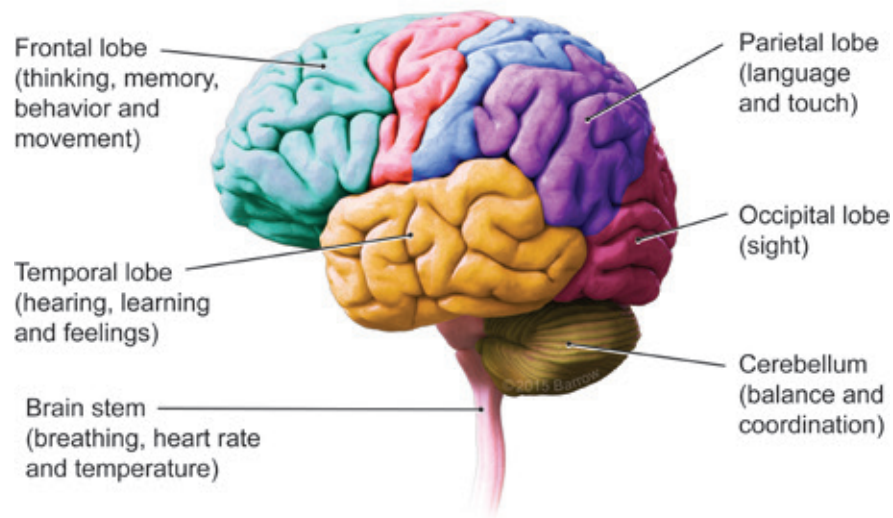


Figure 3. Areas of the brain and their functions.

Dementia with Lewy Bodies

What is Lewy Body Disease?

Lewy body disease is an umbrella term describing two related diagnoses: Parkinson disease dementia (PDD) and dementia with Lewy bodies (DLB). Both PDD and DLB were originally considered neurologic diseases; however, they are now classified as “neuropsychiatric disorders,” a combination of neurological and psychiatric/emotional symptoms. Neurological symptoms include movement symptoms, such as tremors that appear particularly in the dominant hand when resting, postural instability, muscular stiffness or rigidity, and generalized slowness. Mental health conditions associated with PDD and DLB include depression, anxiety, loss of impulse control, and changes in the level (increase or decrease) of emotions.

Cognitive problems occur in over 50% of people with DLB and PDD, such as changes in attention, concentration, task completion, visual and spatial perception, language abilities, and problem-solving. Later in the illness, more serious cognitive issues arise, including visual hallucinations, delusions, agitation, confusion, memory loss, and aggression. Cognitive deficits tend to be worse for people whose predominant symptoms are bradykinesia (slowness) and rigidity (stiffness). People who report tremor as their predominant symptom report less severe changes in thinking and memory.^[3]

What is a Lewy Body?

Lewy bodies are the hallmark changes in DLB and PDD. Lewy bodies are microscopic changes that occur within the nerve cells; the ones associated with PDD originate in the brain stem (the area nearest to the spinal cord) and primarily affect movement. Lewy bodies found in the cerebral cortex (the upper, thinking part of the brain) do not directly cause dementia but act by reducing the threshold for dementia from other causes, such as cerebrovascular disease and large or small strokes. Interactions of other risk factors have less of a direct impact on the nerve cells.^[4]

DLB affects about 1.4 million people in the U.S. Many cases have complex presentations that change over time. Symptoms are noted from multiple areas of the brain, including many of the following.

- **Movement**

- Asymmetric involuntary movements (meaning one side of the body is more affected than the other) when resting or moving; involuntary movements tend to occur in one or both hands and, as a general rule, the dominant hand is more affected
- Stiffness or rigidity in the limbs and/or neck
- Changes in walking, such as shuffling, shortened stride, and occasional imbalance
- Reduced arm swing and stooped posture
- Reduced blinking
- Masklike face
- Slowed and unsteady movements

- **Task Performance**

- Loss of executive function is the inability to set a goal and perform the necessary tasks in the right order to reach the goal. This inability affects complicated tasks, such as taking medications as prescribed (in the right order and on time), and progresses over a period of years to impact simple activities such as eating.
- It is important to understand that **the more the person needs to concentrate on the sequence of activities in the task, the more difficult it is for them to complete it. Asking the person to “try harder” makes the situation worse.** If you try to teach the steps to complete the activity or call on them to remember, it only frustrates you and temporarily adds to the person’s disability. The frustrating part is that executive losses are not stable. The person may be able to do the task for two or three days and then fail. They may regain the ability several days later. This intermittent loss frustrates care partners who often label the person as “willful” or “rude” instead of understanding the disability. A more reasonable approach is to offer to help or stop the activity, distract the person from the activity, and try again later with additional help. Keep in mind that the person is trying as hard as they can, and offer encouragement and positive feedback.

- **Autonomic Nervous System**

The autonomic nervous system is responsible for keeping the body safe and in balance. Losses in this system can lead to the following:

- Loss of or smaller involuntary/automatic movements
- Dysautonomia (meaning malfunctioning of the autonomic nervous system) results in impaired bladder function causing incontinence (lack of bladder control), delayed gastric (stomach) emptying, and constipation.
- Orthostatic hypotension is a drop in blood pressure when rising to stand or sit. It may be accompanied by falling, fainting, or near fainting. On each health appointment, providers should check the blood pressure twice: while sitting or lying and then two to five minutes after standing. If the blood pressure falls 10-20 points, a fall or near-faint can result. It is particularly important that the person is taught to wait and sit a few minutes after rising while the blood pressure adapts.

- Bowel function should be monitored. Constipation may be prevented by four interventions:
 1. Daily aerobic exercise for 20-30 minutes
 2. Increase fiber intake (for example, give two oatmeal raisin cookies per day, which most patients enjoy)
 3. Encourage increasing fluid intake to about one quart per day^[5]
 4. Over-the-counter medications such as polyethylene glycol (MiraLAX) may be helpful in preventing constipation with hard, dry stools by maintaining moisture. Discuss options for constipation with the person's primary care provider.
- Monitoring bladder function is important to prevent infections. Fluid intake should be encouraged while the person is awake to "wash out" the bladder and increase the sensation of needing to urinate. Many elders are reluctant to increase fluid intake, fearing the loss of urinary control. This thinking may result in bladder infections, a very common cause of delirium and agitation. If the person has a sudden increase (meaning several days to one week) of confusion and agitation, always suspect a bladder infection and seek immediate medical help. Untreated infections can lead to sepsis and death.
- Reduced perspiration may result in higher body temperature in the summer. Care must be taken to change to lighter weight clothing and to increase intake of cool fluids.



- **Medications: Increased Sensitivity**

People with DLB become increasingly sensitive to medications, especially those that affect the brain and nervous system. The sensitivity may present as a drug overdose despite using the smallest possible dose of the medication.

- Symptoms of medication sensitivity may include the following:
 - ♦ Incontinence
 - ♦ Low blood pressure upon standing
 - ♦ Muscular contractions or cramps
 - ♦ Falls or near falls
 - ♦ Constipation
 - ♦ Difficulty swallowing
 - ♦ Increased confusion
 - ♦ Agitation
 - ♦ Severe restlessness with constant moving
 - ♦ Akathisia (constant internal need to move about)
 - ♦ Drowsiness, daytime sleepiness
- If the person has a variety of the above symptoms after a new medication (usually an “atypical antipsychotic”) is started or the dose increased, the problem may be a very serious idiosyncratic effect called “neuroleptic malignant syndrome” (NMS). **Symptoms can include the following: fever, muscular rigidity, altered mental status, malaise, headache, and high blood pressure. The person should be taken to the nearest emergency room as soon as possible for evaluation if these symptoms occur.** NMS is a rare, but life-threatening idiosyncratic reaction, not a drug allergy. NMS often occurs shortly after the initiation of neuroleptic treatment or after dose increases.
- Because of the high potential for drug sensitivities, people with DLB should have supervision or adaptive devices when taking medications. The supervision may take the form of time and date containers that families refill weekly, monthly dose packs prepared by local or online pharmacies, or special containers that notify family if the medications are not taken. The best monitoring systems are ones where family members or friends give the medications and keep a journal. If more than one person helps with giving medication, it is best to have a record with time, date, and medications given in a clearly visible spot.
- If the person has issues with swallowing or refuses essential medications, it is helpful to have access to a compounding pharmacist. A compounding pharmacist is one who can reformulate medications to have instant dissolving tablets or syrups in the case of swallowing difficulties. You can find a compounding pharmacy by checking with your local hospital or do a web search for your area.
- Giving medication is a complex task that should always be monitored by the caregiver, family member, or friend. **Mixing medications with food should be avoided, especially in DLB, because it can change the taste of the food. The person with DLB may develop paranoid ideas that the caregiver is trying to poison them. Paranoid ideas are common in advanced DLB, and care must be taken to minimize the potential to trigger them. Rapidly dissolving tablets are a better option. They rarely add unfamiliar or bitter tastes and do not lose efficacy if dissolved.**
- People with dementia often have a decreased sense of time and may skip doses or take too much medication. This issue increases the potential for a serious adverse drug effect. **If the person**

with dementia lives alone and has no regular medication oversight, their physicians should be notified in order to minimize the number of prescription medications given.

- If the person has an adverse effect to a medication, contact the provider who prescribed it. Report the medication, and describe the side effect and any other changes you noticed. This process may involve a visit to the provider or an emergency room. Do **not** give another dose unless told to by the prescriber and you can remain with the person to watch for any reactions.

• Perception

- Visual and spatial disturbances include loss of depth perception and loss of ability to perceive (attach meaning to) objects moving across or in the field of vision. Essentially, the eyes continue to “take the picture,” but the brain doesn’t “develop the film correctly.”
- Visual and spatial perception affects everything: walking; performing tasks; using tools, kitchen utensils, or appliances; climbing or descending stairs; and walking on uneven surfaces. Because it affects the brain rather than the eyes, it cannot be fixed with corrective lenses or surgery.
- The person with visual and spatial awareness deficits may see visual images that are misinterpretations of actual stimuli, such as images or stories on television. These missed perceptions are not hallucinations or psychosis. They are sensory mistakes of interpreting things that are seen or heard. They rarely are a cause of aggression but can be annoying for the care partner.
- As a general rule, we gently explain the phenomenon to the care recipient, allowing the person to express their fears and concerns. People with early to moderate DLB often have good to fair insight into their condition. Many people with DLB (and other dementias) express concern and fear that families will abandon them to old-fashioned, highly restrictive residential facilities or mental health institutes. It is very important to reassure the person that you will be there for him/her for the duration of the illness. This response does not mean you will never place him or her in an assisted living home. It means you will stay involved and provide love and emotional support.

Assessing Visual Perception

Two quick and easy tests can help you to see if there might be deficits in visual and spatial perception:

1. Clock Drawing

- ♦ This exercise (Figure 4) is a simple test. Give your person a blank sheet of paper and ask them to draw a clock. Ask them to put all of the numbers on the clock and to draw the hands set at 10 past 11. Once you finish giving directions, be quiet. Give no hints or tips. If your person is struggling, you have the information you need – perception is impaired.
- ♦ In examining your person’s drawing, look for the following: (1) The clock should be round and closed. (2) The numbers should be inside the circle and in the right quadrant. The first quadrant should contain a 2 first (one-half of

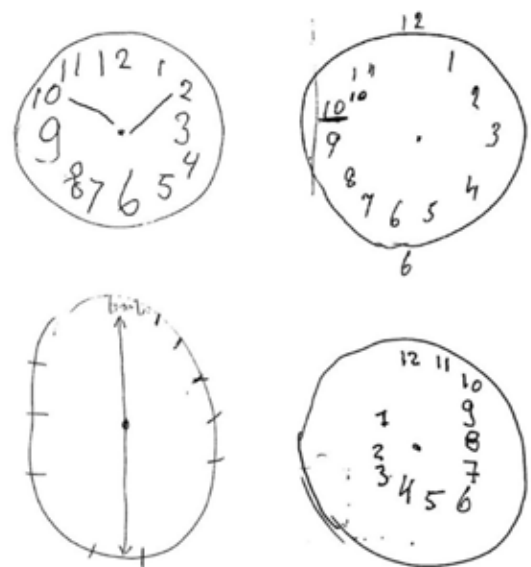


Figure 4. Clock drawings.

the 12), and then the 1, 2, and half of the 3. (3) The long hand should be just slightly past the 2, and the short hand should point toward the 10.

- ♦ If the person or their clock seems odd, ask them to explain it to you. Make a note or two of the explanation on the paper. This action helps both you and their health care provider to understand what the person understands about it. Does he or she understand the clock isn't quite right? Can the person tell you how to correct an error? It is important not to try and correct the person, "coach" them through it, or "teach" the person to draw it correctly.
- ♦ The hand-drawn clocks are invaluable in determining potential safety issues and plotting the disease progress over time. Date and keep them. Take them with you to physician appointments. The clocks help you to see how distorted your person's perceptions might be and whether the person should be allowed to drive, operate equipment, or cook.

2. Copying a Cube

- ♦ This test helps you to check whether the person's depth perception is affected. Give the person a piece of paper with a cube, like the one in Figure 5. Ask the person to copy the cube.
- ♦ If you are drawing the cube for your person to copy, draw two squares, and then connect them with lines that connect the corners. Figure 5 (left image) shows the correct cube drawing. This drawing seems like an easy task because all the person has to do is copy! In fact, it is a difficult task. If you note the person is struggling, take the paper and put it in your file with the clock drawings.
- ♦ If your person has difficulty drawing either the clock or the cube, do not repeat it, as practice will not improve their ability to draw or copy. Trying to have your person practice will only serve to point out the person's losses and cause frustration.



Figure 5. The Cube

Visual and spatial perception is especially important to consider if the person continues to drive.

People with any dementia who insist on driving should be tested routinely to make sure they perceive stop signs and other traffic signals, respond appropriately to oncoming traffic including driving in the correct lane, and do not become lost in familiar areas. If the perception is abnormal, the family may need to work with the Motor Vehicle Department to enact driving cessation to prevent unnecessary casualties.

Many urban areas have services available to test a person's ability to drive. These may or may not be covered by the person's health insurance but can be very helpful in the driving cessation process as people view the testing agency as "objective and unbiased." The person can be re-evaluated routinely or if changes are noticed.

Psychosis in Dementia with Lewy Bodies

Psychosis is a hallmark symptom of DLB, indicating the presence of visual or auditory (hearing) hallucinations. The person is seeing or hearing things that are not there. Most hallucinations in DLB are visual, such as seeing non-existent people or animals in the house. The person may or may not recognize that these images are hallucinations or may think they are real. Hallucinations are often triggered by medications, such as those given for Parkinsonism, opioid pain medications, anticholinergics (to control bladder urgency), muscle relaxants, and benzodiazepines. Hallucinations may also be triggered by infections, particularly bladder infections, impaired nighttime sleep, or excessive daytime drowsiness. Attention should be paid to sleep hygiene, such as observing a nighttime routine and diagnosing and treating sleep apnea.

Hallucinations may also be triggered by environmental factors such as television or family pictures hung in the bedroom. It is not uncommon for a person to think that children are in the house or that grandchildren are sleeping with him or her. If the pictures are removed for a few days, often the hallucinations go away. It is very important to ask the person about the illusions: *“What are you seeing?” “Do the images talk or give you directions?” “Are the images frightening?” “Do you understand that others don’t see the images?”* It is important to keep the dialogue going in order to determine whether there may be increasing agitation and could be dangerous. You do not want to convince the person that these are a psychosis by tapping into fears of “going crazy.”

If your person begins to find the images frightening or begins to incorporate you into the psychosis, seek medical help immediately. Antipsychotic medications or a brief acute psychiatric hospitalization may be indicated to keep you safe.

Delusions are fixed false and irrational beliefs. Often, they have a theme such as burglars or spies living next door and posing as neighbors. Accusing a spouse of infidelity is common. Many delusions are triggered by watching television shows such as raucous game shows, dramas with violent or threatening content, talk shows with contentious or suggestive content, constant news feeds, shopping networks, “judge” shows, and investment television. Families need to be aware of the potential for delusions and limit television to a few hours per day and avoid disturbing programming. Television should never be the primary activity for the person.

Another form of delusion is “Capgras syndrome,” where the person does not recognize their caregiver. The person states the caregiver or family member is an imposter. This problem can be treated with medications.

Once a delusion becomes apparent, steps should be taken to limit exposure to the trigger. Delusions are “fixed beliefs,” meaning that you cannot reason with the person or talk them out of it. This situation is where the use of supportive services, such as adult day health programming and respite providers, are invaluable. As a family member or care provider, you will want to pay attention to the content of the delusions. If the person becomes angry or threatening, seek psychiatric care for them without delay.

Apathy

Apathy (a loss of motivation), depression, restlessness, insomnia, and anxiety are all common in DLB.

These symptoms are attributable to mood reactions from having a degenerative brain disease, and all are also linked to specific changes in the brain and changes in dopamine levels. Treatments include dopamine replacement therapies in addition to activity programs.

Sleep Changes

Sleep changes are a hallmark of DLB. A REM sleep disorder is one in which people act out their dreams instead of going limp while dreaming. Such dreaming can include talking, kicking, punching, and acting out in other ways. This disorder can occur years or even decades before other DLB symptoms happen. Other sleep alterations include the following:

- Excessive daytime sleep, which is thought to be the result of poor nighttime sleep, sleep apnea, repetitive leg jerking during sleep
- REM sleep disturbances (acting out dreams)
- Nighttime hallucinations or delusions

These sleep changes can be relieved using the principles of sleep practices and medications.



Memory

- Memory changes may fluctuate and are generally milder than in AD.
- Fluctuations occur in alertness and decreased mental organization.
- Insight is relatively preserved but fluctuates.
- Psychotic symptoms, including paranoid ideas, visual hallucinations, and delusions (fixed false beliefs) may be present. Hallucinations often occur late in the day or at night with the person reporting people or animals in the home. Medications and television may worsen the illusions.
- Daytime drowsiness may cause the person to become difficult to arouse.

Medical Treatment for Parkinsonian Features and Behaviors

- People with DLB can be exquisitely sensitive to medications, especially drugs used for movement disorders and/or behavior. A general rule is to use fewer, rather than more, medications.
- In treating the movement disorder, newer drugs are sometimes not as good as older ones. Carbidopa/levodopa (aka, Sinemet) is by far the most effective medicine for treating Parkinsonism, especially when attempting to improve function for an exercise program, but caution is necessary when considering a second dopamine-enhancing drug due to increased risk of psychosis (hallucinations, paranoid ideas, and delusions).
- Treatment with more than one medication can make treatment recommendations more complex.
- Treatment of one problem may have unintended consequences in another area.
- Do try cholinesterase inhibitors.

- Avoid dopamine agonists. They don't work and can produce psychosis. They may trigger compulsive gambling, spending, eating, and compulsive sexual drive when these behaviors had not been present in the past. Additionally, mild swelling in the legs and drowsiness can be side effects.
- Avoid anticholinergic medications because they can increase confusion.
- Use antipsychotics only as a last resort, selecting those with minimal anticholinergic effects and low risk or tardive dyskinesia.

Non-pharmacologic Treatment of Dementia with Lewy Bodies

- Aerobic exercise
- A calm, structured routine with activities and tasks following a similar daily order
- Meaningful activities

Helping the Diagnostician

A diagnosis of dementia is a process that may take several years, especially if the person is early in the disease. Some types of dementia change over a period of several years. It is typical for someone to be diagnosed with AD one year and then be diagnosed with another type of disease, such as DLB, several years later because it can take several years for some of the key symptoms to be revealed. Therefore, the family should be sure to report changes seen over time to the person's doctor. It is helpful to keep a journal of symptoms and behaviors to recognize this change.

Acute psychiatric crisis may occur as a result of psychotic symptoms. A psychiatric crisis can present as severe fluctuating agitation with frightening delusions and vivid hallucinations. It may result in violent or dangerous behavior, leaving others, especially care partners, at risk of serious injury. Psychiatric crises may be triggered by infections in the urinary tract causing delirium, responses to medications, poorly managed pain, or unstable medical conditions. An acute psychiatric crisis usually requires hospitalization for treatment and psychiatric medication for stabilization.

An overriding concern with an acute crisis is the person's fear, which can make them feel like they need to use violence or weapons to protect themselves. When a person has DLB with psychosis, there must be a concerted effort to rid the residence of weapons, including guns, knives, and fireplace pokers. Chain saws and other potentially hazardous appliances must be considered a part of this safety plan along with anything else that can be used as a weapon. If guns or weapons must be housed in the residence, remove all ammunition and place both the weapon and ammunition in a locked gun safe. Lock the keys in a location where the person will not find them. Due to paranoid ideas, the development and implementation of the safety plan should be accomplished without the person's knowledge. Removing weapons is often an emotional event that can make the paranoid ideas worse.

Frontotemporal Dementia

Frontotemporal lobar degeneration (aka, frontotemporal dementia or FTD) is a condition that affects the front (frontal lobes) and the sides (temporal lobes) of the brain (Figure 6). The first symptoms often involve changes in personality, behavior, judgment, planning, and social functioning. Individuals may begin to make rude or inappropriate remarks to family or strangers. They may make unwise decisions about finances or personal matters and may be prone to excessive eating or sexual disinhibition.

Some individuals may demonstrate difficulty with language that can include the inability to produce a sentence or not be able to understand what is being said. Hallmark behavioral symptoms of FTD include the following:

- A lack of insight about their condition
- Narcissism or self-absorption
- Decreased attention and concentration

Frontotemporal Dementia:

Behavioral Changes in Middle Age

When middle-aged people present with a chief complaint of behavioral changes, their physicians have several options; most often, physicians recommend consultation with a psychiatrist. People with such behavioral changes are often diagnosed and treated for depression, bipolar disorders, or marital discord. While some people improve slightly with treatment, many do not. These people can go through several years of different psychiatrists and various psychiatric medications, yet they continue to be resistant to treatment.

Another diagnosis rarely considered is FTD, which affects 50,000-60,000 people in the U.S. With FTD, the age at onset ranges from 21-80 years; however, 60% of people receive the diagnosis when they are 45-64 years of age.[6] Approximately 40% of people with FTD have a family history of it, and in 15-40% of people, a causative genetic mutation can be identified. FTD progresses faster than AD, and people with FTD have a more rapid decline over five to seven years.[6] As the condition spreads throughout the brain, both sides become affected. All patients demonstrate language and behavioral problems. Others develop degeneration of the motor strip of the brain, which produces amyotrophic lateral sclerosis (ALS), with significant changes in movement and muscle control. These people have more rapid progression of early symptoms. About two to three years into FTD, the motor symptoms such as uncontrolled muscle twitching (referred to as fasciculations and fibrillations) are noticed, especially in the chest muscles. The person's lifespan is greatly diminished once motor symptoms are present.

What Does Frontotemporal Dementia Look Like?

People with FTD can present with one year or more of behavioral or language changes. Behavioral symptoms are asymmetric, meaning one side of the brain is more affected than the other. Therefore, people with the condition can present with several forms of language loss or behavioral changes.

Behavioral changes include decreased attention and concentration, little or no insight, narcissism, a lack of empathy or concern for others, disinhibited actions, obsessive/compulsive behaviors, and inappropriate social or work behavior. There is a loss function due to the inability to plan and organize tasks (aka, decreased executive control).

Families often complain of excessive spending or gambling, job loss with no insight, rudeness, and apathy. It is fairly common to see people insist on divorce despite years of marital stability. There are often inappropriate sexual behaviors. Some begin to roam, which may involve a continuous pursuit of

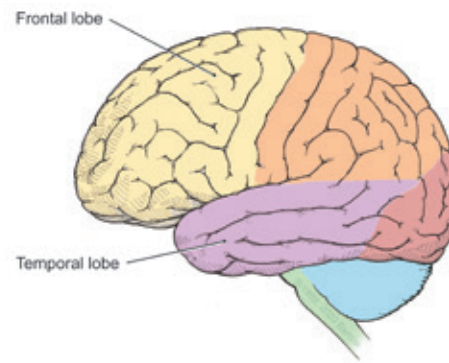


Figure 6. Lobes of the brain affected by frontotemporal lobar degeneration.

movement by car, bicycle, or walking. Many people develop spontaneous urinary and fecal incontinence early in the disease when in highly stimulating situations such as the supermarket, a restaurant, travel, or a family gathering.

Language changes include decreased ability to form words, a tendency to repeat words and phrases, and difficulty understanding written and spoken language. There may be problems with swallowing.

Memory is generally spared in FTD. As a result, these people do well on standard memory screens. However, patients with frontal lobe symptoms who have memory loss are thought to have AD.

Diagnosing Frontotemporal Dementia

The doctor may consider an evaluation for FTD when a family member of a middle-aged person begins to notice unexplained behavioral changes, severe enough to result in the possible loss of a job or

contemplation of ending a marriage. They will perform a diagnostic evaluation similar to an evaluation for AD in terms of history, physical, mental status assessment, laboratory tests, and neuroimaging.



Brain imaging may show atrophy of the frontal lobes that is disproportionate with the age of the person and is worse on one side. Metabolic FDG-PET imaging (fluorodeoxyglucose-positron emission tomography) is helpful in demonstrating decreased glucose metabolism in the frontal and temporal lobes.

The neurological evaluation may demonstrate the return of primitive reflexes, including glabellar, palmomental, and snout reflexes. The mental status testing will probably be normal.

Use of the 30-question Montreal Cognitive Assessment (<http://www.mocatest.org/>), is a

good test that is sensitive to the loss of executive function. Detailed neuropsychological testing focused on the diagnosis of FTD can also provide additional evidence of changes in attention, executive function, and language use.

If You Suspect Frontotemporal Dementia

The physician should meet with both the patient and you. If you would like a second opinion, ask for a referral to a behavioral neurologist or geriatric psychiatrist. An interdisciplinary program where FTD is understood and specialized management is available can help the person and you over the course of the illness. A basic interdisciplinary team includes a geriatric psychiatrist, behavioral neurologist, advanced practice nurse, and a social worker.

Cholinesterase inhibitors should be avoided, as they are associated with increased behavior problems, anger, and rage.

Most important, the family will benefit from access to coordinated care that includes ongoing FTD education, strategies to prevent fiscal catastrophes, planning for care needs, family support, and techniques to manage behavioral symptoms.

Behavioral Changes with Frontotemporal Dementia

Behavior changes are both the hallmarks and challenges of FTD. Most behaviors are simply symptoms of the disease yet are misunderstood when caregivers and providers expect a presentation similar to AD. They also may be dangerous or annoying.

When confronted with new issues of a person with FTD, the first and most difficult thing is to understand that the issue may be a disease-related symptom. One way to make this task easier is to ask yourself the following questions:

- What exactly does the behavior look like? Is it different than the behaviors you've seen before?
- Describe it in a few words. This description will help you when talking with a health professional and seeking help.
- On a scale of one to 10, with one being the least and 10 being the worst imaginable, decide how bothersome the behavior is and write it down.
- Write down what your person was doing earlier in the day before the behavior occurred.
- What was your response to the behavior? Did it help or make it worse?
- Has the behavior happened again?
- In solving these issues, please remember that punishment is never the answer!
- For more advice, contact www.theAFTD.org or the Frontotemporal Dementias Info and Support Group on www.Facebook.com. Potential members must join the Facebook group in order to participate.

Vascular Dementia

VaD, often in combination with AD, is a deterioration of mental function caused by multiple strokes (infarcts) in the brain. There are about 1.3 million people in the United States affected by VaD. The onset of VaD may appear suddenly, depending on the size and location of the strokes. Although VaD is not reversible, treatment of risk factors, particularly high blood pressure, may modify or slow the progression. Losses of function, memory, and language may appear much like in AD. Although these losses are due to continued strokes, sudden changes may be more evident.

Several characteristics are common in VaD and are helpful when distinguishing the diagnosis from AD:

- Symptoms may have a sudden onset and progress in a stepwise pattern, where there are longer periods of stability between periods of worsening. Careful adherence to the medical/dietary/exercise regimen may slow disease progression.
- The person with VaD often has a higher degree of awareness of their limitations than people with AD.
- The person with VaD may have more emotional instability than those with AD.

- People with VaD tend to suffer more depressive symptoms than people with AD, thought to be due to the awareness of their disease.
- People with VaD often have focal neurologic findings, including specific localized areas of weakness or loss of sensation. They may have motor abnormalities that are confined to a single side of the body, such as right-sided weakness or hyperactive reflexes on one side.
- People with VaD tend to have issues with poor recall but not with recognition memory.

Life expectancy for someone with VaD is highly individual and depends on the nature of the vascular problems that are causing their dementia, along with the person's age, other medical conditions, and how well they adhere to the principles of their care program. Care programs for people with VaD are similar to those for people with AD.

Treatment of VaD primarily focuses on managing the health conditions and risk factors that contribute to VaD. Controlling conditions that affect the underlying health of the heart and blood vessels can sometimes slow the rate at which VaD gets worse. It may also help prevent further decline. A diet and exercise program, as well as maintenance of a healthy lifestyle (e.g., avoiding smoking and excessive alcohol intake), is vital to managing VaD.

Depending on the person's individual situation, the doctor may prescribe medications to:

- Lower blood pressure
- Reduce cholesterol level
- Prevent blood from clotting and keep arteries clear
- Help control blood sugar if the person has diabetes

Cognitive enhancers used in AD may also be prescribed to help reduce the rate of cognitive and functional decline. However, these medications are not specifically FDA approved for the treatment of VaD.

SECTION THREE— Care Issues as the Disease Progresses

Okay, so you're caring for a loved one with a dementing illness. Now what? As the disease progresses, life becomes increasingly complex. There are things you need to know to understand how the disease presents and what things need to be accomplished, both early and later on. The earlier the planning and the more you discuss it with your person, the easier it will be to develop a plan that is satisfactory to you both and the more likely the person's desires and concerns can be made known and incorporated into the plan.

Developmental Regression

Developmental regression occurs with disease progression and stress. One issue in communicating with your person is to remember that coping skills and understanding diminish over time. This situation means that while your person is an adult, their level of understanding and ability to reason and be flexible will change depending on the type and stage of the illness. Something as simple as fatigue can temporarily change how well the person understands what you are saying or asking. When stressed, your person may regress to the level of understanding of an adolescent or child. In advanced disease, this problem becomes more evident as there is a return of the “primitive” reflexes that disappeared in the first year of life.

Fear of Abandonment and Nursing Home Placement

Many people with dementia have a fear of abandonment and nursing home placement. They may perceive residential care to be the more primitive care environments of the 1950s. People with dementia often reject the idea of visiting an adult day health program, assuming they will be treated like children. Visits often demonstrate active well-balanced programs. It is important to speak with your person frequently and kindly reiterate that while he or she may eventually need help for care, you will be there for them and have no plans to abandon them.

Decision-makers

What is a Decision-maker? How Do We Find One?

Adults live in a world filled with dozens of daily decisions. These range from when to eat and take medications, how to spend time, where to live, how to manage money, whether to drive, what to shop for, and how to manage an estate. Slowly, dementia erodes the person's ability to make complex and, eventually, simple choices. This necessitates having a decision-maker. The decision-maker must have a completed form called a “durable power of attorney” (DPOA), which enables them to intervene, speak with health providers, hire care partners, pay bills, and decide where the person with dementia will live. The DPOA form is completed and signed by the person with dementia, identifying what they will allow and limit the DPOA to do for them.

DPOAs are often a spouse or close family member. It is important to understand that having a spouse does not grant immediate access to medical information, nor will telling medical staff you have the form

at home. Care partners must carry several copies of the DPOA form wherever they go so that they can provide proof that they have a DOPA. Health care providers will want a copy of the DOPA.

If the person needs a decision-maker but refuses assistance and the living situation might be hazardous, the family or others might file a petition for guardianship or conservatorship with the court. These are involuntary court orders to either manage the person's living situation or estate.

Each state has laws regarding who can make decisions and when for people who are incapacitated. Although each state has unique decision-making standards and policies, most states are consistent about who can serve as a decision-maker and what they can do (Table 4). A decision-maker is a person or people whom the person with dementia designates to make some or all of the types of decisions shown in Table 4. A person who has accepted becoming a DPOA can resign, or the patient can withdraw the DPOA.



Table 4. Decision-makers in Dementia Care

Type of decisions	Who Decides and Applies	Is the court always involved?	Type of decisions	Reports to the court?
Health Care Durable Power of Attorney Person with illness decides who will serve	Can be professional, family, friend, attorney, trust officer, or anyone	No Materials for application are available free on AZ Attorney General's website and may be filed/stored with AZ Secretary of State	Medical care and treatment, communicates with medical professionals, where person will live, what programs to attend	No
Guardianship	Court considers petition by family or others during a hearing; court appoints a guardian	Yes; court-appointed after the court declares the person is "incapacitated" May still be a family member	"Parental" types of decisions	Annual report of how all needs are being met
General Durable Power of Attorney	Person with illness decides who will serve; often family or friends	No; some banks require a witness or notary	Medical care and treatment, communicates with medical professionals, where person will live, what programs to attend	No
Conservatorship	Court-appointed conservator after person is declared "incapacitated." Conservator is often a family member	Yes; court-appointed after a court declares person is "incapacitated"	Financial and estate management	Annual report of how all needs are being met with all receipts
Mental Health Durable Power of Attorney	Person with illness decides who will serve	No	Allows durable power of attorney for admission to psychiatric acute care unit	No

What is a “Durable” Power of Attorney? How Does It Differ from a Standard Power of Attorney?

A standard power of attorney (POA) is given by a person to another in order to carry out a function, such as selling a car. The POA is only enforced because both parties are fully capable of making the agreement and carrying out the task. If one of the people is incapable of carrying out the agreement, the POA is dissolved. A “durable” power of attorney has a statement that the DPOA will remain valid even if the person becomes incapacitated. This detail helps to assure that help can be hired, bills paid, and essential tasks can be done without the person with the disease firing the person serving as POA. The earlier in the disease the powers of attorney are signed, the easier it is for the person with dementia to participate in decision-making.

Who Becomes a Durable Power of Attorney?

Family members, including spouses, siblings, adult children, other relatives, partners, and long-time friends are common. There are several cautions about assuming the DPOA responsibilities:

- The DPOA should be well known to the family.
- A background check is essential before an agreement is signed.
- The DPOA should reside in the same state as the care recipient and see them regularly. In some cases, a family might divide the responsibilities with a primary DPOA to help with living and care and a secondary DPOA to manage finances.
- There should be supervision of the DPOA because the person may have access to the person with dementia’s money and assets.
- There should be a legal agreement about fees and responsibilities.
- If deciding to use an attorney for help with the development of advanced directives, wills, trusts, guardianship, conservatorship, and/or applications for Arizona Long-Term Care Services, you will want an attorney who specializes in “elder law.” Find a listing of elder law attorneys by contacting the Arizona Bar Association (<https://azbar.legalserviceslink.com/>) or the Desert Southwest Chapter of the Alzheimer’s Association.
- It is important to understand that only a judge can declare a person incapacitated following a competency hearing. These hearings are mandatory for awarding guardianship and/or conservatorship.
- Physicians and attorneys do not determine competency. Competency hearings mandate that the person be represented by counsel and have the right to appeal the outcome.

The decision-making capacity may be significantly impaired early in the disease, such as with FTD. Or, the person can lose the ability to make decisions slowly, such as with AD. Ongoing conversations about the person’s capacity should be held as soon as the family notices judgment issues and periodically with the person, caregiving family, and health provider. Many family members are reticent to discuss the disease with the person who has it for fear they will depress the person or cause the person to “give up.” Keeping a dated journal where incidents of poor judgment are recorded can be shown to the provider during visits rather than discussing mistakes in conversation. Many people with dementia know they have memory loss and are willing to talk about it in at least general terms. You do need to go slowly with the discussions and use terms the person can relate to. It is more important that the person can say “memory loss” and demonstrate understanding of the concept than admit to “Alzheimer’s disease.” The

one critical exception to the person having insight about their illness is with those with FTD. People with FTD have a lack of insight (anosognosia), and there is nothing you can do to teach them to change their lack of understanding.

What are Common Health Decisions for Someone with Moderate to Advanced Dementia?

As the symptoms of dementia become more severe, the decisions the person and family must make involve a choice of types of care interventions. In a previously healthy person, we usually expect to pursue illnesses aggressively with medications, surgery, and other treatments unless the care plan is rejected by the patient. In moderate-to-advanced dementia, the decisions about goals for care change to center around the use of comfort care (aka, palliative care). Care providers and the family begin to recognize that dementia is a terminal illness and make decisions regarding whether interventions, such as diagnostic procedures, chemotherapy, medications to prevent cardiovascular disease, surgeries, feeding tubes, hospitalizations, and cardiopulmonary resuscitation (CPR) will promote the quality of the person's life or simply make life longer.

The decision to use palliative care is complicated. Family members and health providers may not agree due to religious, spiritual, cultural, or practice beliefs. For example, a physician may feel it is unethical to stop doing annual mammograms and colonoscopies (tests for colon cancer requiring rigorous preps) or stop administering statin medications, despite the slim chance the person will live long enough for the medication to have the desired effect. Additionally, cultural and spiritual beliefs are powerful influences on decision-making. Some spiritual-centered institutions regard palliative care decisions as “giving up” or hastening death.



Common examples of decisions include the following:

- CPR involves efforts to maintain the heartbeat and breathing in the event of a cardiac arrest. It usually involves the use of ventilators, intravenous medications, and chest compressions, which, when done properly, causes rib fractures. If successful, the person may live a very short time, often sedated and on mechanical ventilation. Families can request a do-not-resuscitate order. This order allows the person to die when the heart or breathing stops, yet it does not eliminate other forms of treatment.
- Patients identify feeding tubes as one of the most uncomfortable procedures they must undergo. As dementia moves into the terminal stage, patients consume less and less food, begin to lose weight, and experience problems with swallowing. Some providers and families demand feeding tubes when there is little evidence the tube will prolong life, prevent infections, or provide comfort. People with

feeding tubes have increased diarrhea, aspiration, and use of restraints.

- As a general rule, hospitals are “inhospitable” places for people with dementia. The change in the environment increases confusion because hospitals lack calmness, predictability, and familiarity. Moreover, hospital stays tend to be short with abrupt discharges that can occur even at night. Alternatives are to have the person cared for at home or at a long-term care center.
- Intravenous hydration may provide temporary fluid replacement; however, it cannot maintain nutrition and causes discomfort. In the absence of nutrition and hydration, the body produces endorphins, which are morphine-like substances that blunt nerve endings. Research indicates that this form of death is comfortable and can be enhanced by supplemental pain management approaches.
- Antibiotics may or may not improve infections, including urinary tract infections and pneumonia, the latter of which is often the most common cause of death due to problems with swallowing. If the decision-maker refuses antibiotics, other comfort approaches can be used to manage discomfort effectively.^[7]

Trying to get the person to “confess” he or she has AD may produce anger and paranoid thinking. Instead, use a gentler approach: “So John, how is your memory these days? What have YOU noticed?” Avoid terms that suggest the person should remember what has been told before. Consider the answers for yourself to the following questions. Try to imagine how you would want someone to ask them of you:

- Who will make decisions for me when I no longer can?
- Who will manage my finances?
- What types of help will I be willing to accept to give my care partner a break?
- Where would I prefer to receive care if and when my family is unable to care for me in my home?

Safety Issues

Safety is a Concern Throughout the Illness When a Person has Dementia

The concept of safety applies not only to the prevention of physical injury, illness, or death but also to financial security. Early in the disease, people lose their sense of what is risky or dangerous. They may have difficulty using cash or credit cards. They may also become vulnerable to financial scams and individuals (including family) who try to gain control of their assets. It quickly becomes the responsibility of the identified decision-makers to supervise, monitor, and set limits. In many cases, the decision-maker also takes over the finances.

Early Disease: Examples of Common Safety Issues Reported by Families

• Financial Issues

- Making bad decisions, managing finances:
 - ♦ *“I found all sorts of unpaid bills and a notice that Dad’s electricity would be turned off! He insists he is paying his bills and only trusts himself with his money now.”*
 - ♦ *“I found Dad’s bank account was cleaned out! He said he was helping the nice lady who comes to his door and helps him!”*
 - ♦ *“There are shipping boxes all over the house containing worthless collectibles!”*
 - ♦ *“We went to the bank yesterday, and his account was empty! No one seems to know what happened.”*

- ♦ *“Dad thinks that solicitation calls, political requests for funds, and requests for charitable donations and magazine subscriptions are bills. He is also gambling online. He doesn’t understand that he is paying for these games! He has sent out over \$550,000 in the past several months!”*
- The best way to prevent financial surprises is to supervise on a regular basis. Sometimes you can give the person gift cards with a set amount he or she can spend. It is important to remember that you are the care partner, not the person’s parent. Set limits *with* the person, not *for* them.
- Put packages in a common place where you can observe what is being delivered. If packages need to be returned, do it quietly. And watch the bank balances.
- Telephone scammers can be relentless. Develop a habit of having the phone off unless you are making a call. Tell your friends you will return their messages. Have caller ID and be aware of new scams as they are reported on news. Investigate scam prevention companies that block calls from unknown callers such as www.nomorobocalls.com.

• **Will My Loved One Become Violent?**

- The idea that people with dementia become violent as a normal part of the disease is false. Although we want to be aware of a potential for aggression, the average person with dementia does not become violent. The most common reports of aggression occur when the person feels overwhelmed or pushed to do something beyond their abilities.
- Several situations can increase the potential for aggression. You are trying to get your person to do something that they don’t want, and your insistence aggravates them. This concern is most common with bathing.
 - ♦ It is important to remember that a bath is just a bath, not a statement of social values. Your person is an adult and can participate in decisions about his or her care. You can suggest postponing the bath until later or postpone the planned outing.
 - ♦ Be creative in planning. You can try hiring a home health aide to administer the bath two to three times a week. One family hired a very attractive aide, who mentioned that the man was also very attractive. The man quickly went into the bathroom and started his bath. When he was dressed his wife told him how nice he looked. The man forgot the suggestive innuendo and went out for lunch with his wife. They repeated this scenario several times over the coming weeks, and he never refused bathing again.
 - ♦ If your person refuses a bath, ask why. Many people with dementia fear having the shower water run over their head. This issue can be managed with shower caps and towels or other methods of bathing, such as towel baths in bed. Others become increasingly modest, a problem easily solved by bathing the person with underwear on and encouraging them to change into warm, dry undergarments as soon as the bath is over. There are several classic films of alternative ways of bathing on YouTube (search [Bathing Without a Battle](#); Pines of Sarasota, 2010). These films are available in several languages. Please see the Recommended Reading and Viewing section.
 - ♦ If there is an activity where a bath is needed, such as a social outing or meal, make your focus the activity rather than the bath. Mention where you are going and what you will be doing. If your person refuses the social activity it may be that he or she knows the activity may be overwhelming.
- Many people with moderate dementia experience difficulty with too much stimulus, especially around groups of people and noisy places. They become fatigued quickly and ask to leave. It is very

important that the care partner recognize the request to leave as a call for help. It is VERY important that you leave when the person asks. Failing to leave can lead to sleepless nights or severe late-day confusion or both.

- If the activity is a holiday, such as Thanksgiving dinner, make extra plans for your person:
 - ◆ Plan to stay for an hour or less.
 - ◆ Think about feeding your person before other guests.
 - ◆ If available, ask to use a spare bedroom with easy chair to allow your person to come and go, getting rest when he or she feels the need.
 - ◆ Do NOT put your person in front of the television with other guests to watch a rowdy football game.
 - ◆ Avoid sitting where political or heated discussions are taking place, especially family conflicts about your person's illness or long-term care plans.
 - ◆ If the host feels they cannot meet these needs, change your plans. Then, next year, you will know to change your holiday plans.
- The person has hallucinations and delusions, especially with paranoid ideas. This condition can be due to the type of dementia, such as DLB, or a secondary condition causing delirium. The most common cause of delirium is an infection, such as a urinary tract infection or pneumonia. The person may be having a reaction to a medication.
- Other sources of delusions and illusions can be media. The person will describe the actions of people they see on television, family pictures, movies, constant watching of news programs, reality television, radio, or other media. This occurrence can be very distressing as the illusions are quite



real to the person. The person may discuss what he or she sees and become upset when the family reports that the illusions do not exist. Family members often interpret the “stories” as falsehoods.

- Delusions are more common if the person has a history of an aggressive personality, a psychiatric disorder, or substance abuse.
- More common than these causes are issues of communication, changes in routine, or too much stimulus, usually noise.

• When Aggression Starts

First, if your person begins to become agitated or aggressive, do the following:

1. **Stop whatever activity is going on.** Be quiet. Do not try to defend your position as this response may make agitation worse.
2. **Make sure you are standing between your person and the door.**
3. **Speak quietly** (but loud enough to be heard) in simple sentences.
4. **Apologize.** You may have done nothing wrong, but it is difficult to argue with someone who is apologizing. *“I’m sorry, Sam. I never meant to offend you. I’m so sorry. I won’t do it again.”*
5. **Agree with the person.** *“You are right; I would be just as angry if the bank took my credit card! I am so, so sorry.”*
6. **Vow to fix whatever is wrong.** *“I don’t have time today, but I will call the bank first thing tomorrow and fix this.”* Then leave the room. Allow for a time-out. This action validates the person’s feelings and can help them forget the problem. Do not bring it up again; if your person brings it up, apologize because you’ve been so busy and repeat steps 4-7.
7. **Do not try to explain, reason, negotiate, or give orders** as it will bring the problem to the person’s attention and heighten the agitation.
8. **Try contacting a supportive family member to calm the person over the phone,** if you cannot calm the situation within 10-15 minutes or the person becomes worse. If that doesn’t work, contact 911 and ask for paramedics to take the person to the emergency room for medical assessment and treatment.

If the person becomes aggressive or violent, consider it to be a medical emergency requiring acute medical assessment and treatment. If left untreated, aggression will become worse, and may require psychiatric hospitalization.

Many families think they can admit an aggressive, agitated person to a nursing, assisted living, or memory care facility; however, they cannot. Residential facilities have no special capacity to manage violence and have more restrictions on the use of mood-altering medications than the family at home has. Admission of an aggressive person to a group environment with other frail individuals could lead to injuries to staff and other residents.

• Are You Safe?

As dementia progresses, abstract concepts such as “safety,” “danger,” and “risk” become increasingly important for caregiving families. The person loses the concept of things that could cause injury or harm. For example, your person may decide to walk to the grocery store after midnight to

get a bag of chips. You discover her missing and go outside where you find her trying to cross a busy street. You bring her back and lecture her on the danger of leaving the house after dark. She agrees. You feel safe until 3:00 am the next morning when you find the front door open. Your loved one is gone, and the closet where a gun is stored is open and empty. You call 911, and police spend the next three hours searching before they find her sitting in a parked car. She still has the gun, but it is leaning on the trunk. The police confiscate it and insist the gun must be removed from the house. You assure them you will speak to your person and that this situation will never happen again.

The next morning you have locks installed on the front and back doors. Having been up all night, you go to your room to take a nap. Two hours later you wake with a start. Your person is standing over you with the fireplace poker. She is confused and does not recognize you. You take her to the nearest emergency department where they find a urinary tract infection, prescribe antibiotics, and send her home. But you are not comfortable, and it dawns on you, *“I am not safe!”* You speak with your family about hiring help or institutional placement, but your family resists that idea stating, *“Mom would hate a place like that. Just call us for help if you need it. I can come over on Friday from 1:00 till 3:30!”*

People with dementia are often unpredictable. Care partners often overlook or dismiss the warning signs of danger because they feel they knew the person before the illness, and they know them well enough to secure the home. The Alzheimer’s Association (2018) reports that more than 60% of people with dementia wander away from home; 94% are found less than two miles from home. Five to 10% of people become violent. Families must admit to themselves that people with dementia are at higher risks for injury or injuring others.

It is very important to discuss potential dangers with a nurse practitioner, social worker, or your provider to develop and implement a risk evaluation and safety plan. Consider the following questions:

- Does your person always know you? Or do they ask you who you are, thinking you are an imposter?
- Are there guns in the house or car or knives in the house?
- Has the person started carrying a potential weapon?
- Does he or she worry about the people coming into your home?
- Do they worry about infidelity?
- Has your person confabulated (made up stories) or reported stories about a neighbor or something they saw on television?
- Has the person started to lose his or her temper for no real reason?
- Has your person made threatening statements about a neighbor, the neighbor’s pet, or children?
- Does your person sleep well at night? Have they woken you up and startled you?

To begin your safety plan, you must admit to yourself that you could be injured and take steps to prevent it. Consider the following for your safety plan:

- Move to a second bedroom with a door that locks. If the door doesn’t lock, purchase an alarm for it. Never let the person come into the room when you are asleep.
- Rid the house of guns AND ammunition. Purchase a gun safe, and hide the key. Make sure sharp knives stay out of sight.

- Report aggressive statements to his or her provider and discuss medications to dampen temper.
- YOU wear an electronic pendant that will summon help if you can't reach a phone or are injured.
- Determine two or three safe places where you could hide until the police arrive.
- Always position yourself between your person and the door.
- Inform your family and friends of the potential danger and your plans to stay safe.
- If the aggression worsens, ask the person's doctor about a geriatric psychiatry hospitalization.
- Have a lockbox on your front door so first responders can rescue you without breaking windows.
- Do not dismiss the task of planning for your safety while thinking such an event would never happen to you or, even worse, while thinking that death might relieve you of this burden. Have a plan to help yourself.

Live-Alones (People with Dementia Who Live Alone)

Autonomy is a primary value in American life. From the time we are in high school, we strive for more and more independence. This value does not decline with age or dementia. Many residential communities are being built to accommodate active, independent, healthy, mostly retired people



in the 55-plus age range. Many of these communities offer little care and support for aging residents. Residents or homeowners move away from their hometowns, family members, and friends until they are too frail to manage alone. Those seniors who don't move find their friends have moved, and thus they too have diminished social resources.

As these active elders age, a considerable number develop dementia. It is estimated that about 1.5 million people with dementia lived alone in 2011.[8] This statistic poses special challenges to families and providers, who tend to think about dementia as memory loss, yet it is the combination of other symptoms early in the disease that challenges the ability

to live alone. Decision-making and problem-solving abilities are impaired. Loss of executive function, the ability to plan and execute small steps to meet an overall goal, and loss of time sense contribute to disorganization. Complicating this condition is a decline in self-awareness about their limitations and decreased attention span.

Losses combine to lead to functional difficulties with the following tasks:

- Paying bills, managing money, and keeping up with the mail
- Driving

- Shopping and making good decisions about purchases
- Using the telephone, computer, and email appropriately
- Performing yard work, chores, home maintenance, cleaning, and cooking
- Participating in social and religious activities
- Initiating hobbies and leisure activities
- Throwing things away appropriately and ridding the home of clutter
- Giving poor care to pets
- Adjusting the thermostat
- Becoming ill from medication errors or failing to take medications as directed
- Fending off financial predators

• **What Can a Family Do to Help the Person with Dementia who is Living Alone?**

Step One: Start talking about it as soon as the disease is detected.

Families need to open an ongoing discussion about what will happen when the person can no longer live alone. Ask questions in the abstract: *“Mom, if the day comes when you can no longer live alone, where would you want to go?”* Even if Mom makes a statement such as, *“Take me out and shoot me,”* she is listening. Do not use the statement as a reason to give up. Revisit the question gently but frequently. Admit that you are as upset by the events as she is, but note that today’s residences and long-term care options are not what they were 10 to 15 years ago.

Locate an elder law attorney who can assist with developing advance directives, including DPOAs well in advance of needing them. Many families assume a spouse or “next of kin” have the same power as a DPOA to review medical records and participating in making health decisions. Unfortunately, this scenario is not the case. Members of the family need to be informed of who the decision-makers are, and if there are special conditions that need to be followed, such as if the DPOA becomes ill and is unable to serve.

Step Two: Try to get the person to accept services in the home.

In-home help is the best way to prolong the ability to live independently. These choices are often tough to make. Many people prefer to move to a residential facility instead of having “strangers” in their home.

Step Three: Recognize that living alone is a temporary solution.

This situation can worsen the person’s symptoms.

If you are a family member and want to determine whether it is time for placement in a care residence, the Live Alone Assessment can help (Table 5). By providing key questions and observations, families can determine when the person is no longer safe to live alone.

Table 5. Live-Alone Assessment

GRADE			
A – Emergency Only one condition needs to be present for immediate help or placement to be required	A/B – Emergency Semi-Emergency Grade depends on circumstances	B – Semi-Emergency More than two conditions indicate there are safety concerns that must be addressed	C – Non-Emergency More than three conditions indicate additional help will be beneficial; re-evaluate monthly
OBSERVED OR REPORTED CONDITIONS			
<ul style="list-style-type: none"> • Weight loss of more than 6 lb or 10% of body weight over 6 months. Evidence of protruding bones • Presence of paranoia, hallucinations, delusions, aggression, or suicidal thoughts • Threatens violence with/without weapons • Evidence of caregiver injury/domestic violence • Repeated ER visits, hospitalizations • Evidence of substance abuse • Frequent calls to police or emergency services • Wandering outside the home • No food or rancid food in the home • Lack of safety with stove, power, and lawn tools • Unable to take medications correctly • Livestock/other animal receives inadequate care • Eviction notice served 	<ul style="list-style-type: none"> • Malfunctioning plumbing • Thermostats not set appropriately for weather conditions • Chronic anxiety, panic attacks, worry, or depression is present • Unsafe driving or refuses to stop driving • Neighbors calling the police 	<ul style="list-style-type: none"> • Not able to manage bowel/bladder care • Repeated calls to family or others asking what to do next • Dirty/infested household • Garbage accumulation • Food stored inappropriately • Taken advantage of by family, friends, neighbors • Refuses personal care for prolonged period of time 	<ul style="list-style-type: none"> • Phone calls from community members advising help is needed • Vegetative or socially isolated behavior (e.g., sitting all day with the television on or off) • Missing belongings, hiding things • Poor grooming, wearing the same clothing all the time, soiled appearance
Total A	Total A/B	Total B	Total C

Hall, G. (2004). *Live Alone Assessment*. Iowa City: University of Iowa College of Nursing.

Driving

Dementia impacts many cognitive functions necessary to operate a motor vehicle safely. It can cause changes in how the brain processes visual information, which can result in the person not noticing things in the environment or not being able to judge distances appropriately. Dementia can also affect attention, memory, multitasking ability, judgment, and response time.

We recommend discussing driving as soon as the disease is diagnosed. The first discussion should focus on safety. Even if the person with dementia is still driving safely, the illness will progress, and driving will inevitably have to stop at some point. Discussing this future event with them and having them identify a trusted decision-maker to observe their driving on a bi-monthly basis continues to give the person with dementia a voice in the discussion.

If the person with dementia continues to drive, they should have a Safe Return/Medic-Alert bracelet in case they are stopped by the police. This bracelet helps to ensure that their confusion is not mistaken for intoxication.

If the person with dementia insists on continuing to drive or there is uncertainty about their ability to operate a motor vehicle safely, we recommend a formal driving evaluation. This assessment should be performed annually to evaluate emerging problems over time.

Anger is an expected response to the loss of driving privileges. Acknowledge the person's frustration and reassure them that you will do all that you can to support them despite this loss. Apologize that they are upset, but remain steadfast that they cannot drive. Refocus the anger on the disease, so that your person stays angry at the disease rather than you.

Providing Care with Dignity: Day-to-Day with Dementia

Okay, you've gotten through the basics of dementing illnesses: types, diagnosis, medical treatment, problem behaviors, disease progression, and safety. The remainder of this booklet will be devoted to issues of day-to-day care: what activities might work for you, what help is available to you, and how to locate it. Common questions will be addressed about how all of this information changes your life as a caregiver.

Dementing illnesses have the potential to strip individuals of the respect they have earned over a lifetime. Achievements may be overlooked when others perceive only a person who makes mistakes, becomes easily confused, has problems with communication, activities, and function. When in public, the person may be treated as a child or may be excluded from family conversations and community activities. There are increasing numbers and types of programs to help.

Basic Environmental Safety

Preparing the environment for safety is important, as the person with dementia tends to lose their sense of danger. As a caregiver, you cannot be vigilant 24 hours per day. Things will happen. The following is a list of basic safety precautions to make day-to-day life more risk-free.

- Rent a post-office box in order to screen junk mail and solicitations.
- Turn water heater to 110 degrees Fahrenheit.

- Remove power tools.
- Hire lawn care, pool maintenance, and snow removal services.
- Avoid having your person change the propane tank.
- Have no guns, ammunition, or hunting knives in the house. If guns are in the house, lock them all away when not in use.
- Pull knobs off the stove when not in use. Remove metal pots and pans from the area surrounding the microwave. Unplug cooking utensils when not in use.
- Make sure you have a fully charged fire extinguisher in the kitchen.
- Remove soap pods filled with laundry detergent and dishwashing detergent. Remove “guest soaps” and other non-food items that could be mistaken for candy.
- Have the person smoke outside in a safe place.

Common Questions and Answers

“Why Does My Person Ask the Same Question Over and Over?”

- Caregivers report that one of the most annoying things about memory loss is when the person asks the same question over and over. Often the question centers around planned activities or appointments. The person has lost confidence in their sense of time and does not want to miss the activity, so they ask, *“When are we going?”* Caregivers report answering repeatedly, but the answer never satisfies. A good approach is to ask, **“Why are you asking?”** The person then gives a different answer, often, *“I don’t want to miss the activity.”* You can then reassure the person that you will make sure they are on time.

“Why Can’t I Get My Person to Sleep at Night?”

- She says she is exhausted but rises after a few hours to walk around the house. There are several reasons why people are up at night. The most common is that they are over-tired from too much daytime activity without rest periods. Try blocking the day into one-hour segments, giving the person one-half to one hour of rest between activities. Turn the television off and direct the person to his or her easy chair for a “snooze.” Take this action mid-morning for one-half hour, after lunch for one hour, and then, if the person is still fatigued, repeat it one-half hour before supper.
- Discuss the use of medications with your physician or pharmacist to see if medications might be adding to the problem. Discuss the potential that your person may be having nighttime pain, such as from arthritis, and might benefit from pain relief medication before bedtime.
- A routine of daily exercise and activities will help to promote a sleep routine. Know the person’s best time of day and plan activities, especially medical or dental appointments or entertaining, for that time. Plan to keep activities brief, about 20 minutes at the most, followed by a rest period.

“My Person Lies All the Time, Making Up Stories We Know Aren’t True.”

- *“How can I convince her to tell the truth?”* The “stories” your loved one makes up are not lies. They are called “confabulations” and are symptomatic of brain damage. Your person does not know the answers to questions or the information you request, so the injured brain makes up a new set of details. Your person doesn’t recognize that he or she has made a mistake. Trying to correct their missed perception can upset them.

- First, ask yourself whether correcting the person is really important. Will it change anything? Probably not. Unless the confabulation leads to danger or risk of injury (such as the person taking the car), it is better to recognize the situation as the result of irreversible brain damage and ignore it. Even worse, you don't want to challenge the person by making them admit they were wrong. That could lead to anger and embarrassment.

“How Can I Convince My Mom That Her Parents Are Dead?”

- Every afternoon we have the same conversation: *“Where is my mother? She should be home from work now, and we need to make dinner for the children. I’m so worried! I have to go out and look for her!”* Consider using these responses: *“Oh! I’m sorry. I forgot to tell you that Mom called and said she was having dinner with her parents. They are bringing her home. Will you please help me set the table? I have either mashed potatoes or sweet potatoes. Which would you prefer? How do you want me to fix them? How about with sour cream?”*
- It is not important to note that the children have been grown with families of their own for many years, and the person’s mom passed away 20 years ago. The timeline is not what is important here. It is the person’s sense of security and dignity that are important.
- If the person continues to fret, taking them for a brief ride in the car to “look for Mom” might be helpful. As soon as she is in the car, change the subject and stop at a bakery or convenience store for something sweet to distract the person. Keep talking about other things.
- Another approach is to have the person phone a family member to reassure them that everything is okay.



“I Want a Candy Bar, NOW!”

- Give the person a small candy bar and change the subject. Yes, they may have Type 2 diabetes, but they also have a dementing illness, a terminal illness. Sometimes the quality of life is more important than strict medical compliance. Remember that you are a caregiving family member and your person’s advocate, not the food police!

“Everything I Say Seems to Lead to an Argument! I Don’t Want to Argue and Fight. How Can I Stop This Arguing? If He Would Just Listen to Me, We Wouldn’t Constantly Get On Each Other’s Nerves!”

- People with dementia tend to remember things that are negative; so, the way to reduce arguments is to diffuse them with positive thoughts and statements that promote forgetting.

Several examples are listed below:

- Person: *"I want to drive, and you won't let me! The doctor said I shouldn't drive, but what does he know? I've been driving for 50 years and never had an accident! What does the doctor know? Give me the keys NOW!"*
- Caregiver response: *"The doctor says we can't have you drive with the changes in your vision, but I can see why you are upset. I'm so sorry about this illness. What is happening to you is unfair. I don't know anything about this vision change. Let's call the ophthalmologist tomorrow and see if anything new can be done to make it better. How about some ice cream now?"* (Of course, you are going to be too busy to call tomorrow.)
- Second: Apologize for upsetting the person. *"I'm so sorry. I wish this weren't happening. We know you haven't done anything wrong."*

"I Am Not Going to Adult Day Programming! That Is for Old People!"

- This reaction is a common response to a question that begins with the words, "Do you want to?" People with a dementing illness often understand that change can result in confusion and, therefore, refuse to participate. Moreover, the person may fear they will be placed in a nursing home and abandoned. The idea of new programs can be introduced but slowly and deliberately. Start by meeting with the administrator and asking for permission to stay with your person for the first three days. While there, act like you are having fun. On the third day, excuse yourself to go to the restroom. Go and stop at the back of the room. Watch to see how your person responds. If he or she panics, perhaps day programming is more than can be handled at this time. If your person doesn't notice that you are gone, then you can proceed with day programming. Ask the day-program staff to help your person to adapt.

"She Wants to Wear the Same Clothing Day After Day."

- Adapting to change can be very difficult for individuals with dementia. This difficulty includes simple changes such as new clothing for the next day. Instead of arguing with your person or trying to convince them to wear something new, purchase several identical outfits. Then replace the dirty clothing with an identical clean set when the person undresses for bed or a shower or bath. Be sure to have a picture of your person in their clothing that you can present to the police in case they wander.

"Why Is She Resistant to Bathing?"

- Many people with dementia go through a phase during which they are reluctant to bathe or become afraid of getting their face wet. This regression is very similar to the reluctance experienced by young children who often fear getting water in their eyes. Your person may also not remember when they last took a bath or showered. Strategies for dealing with this challenge include the following:
 - Consider your person's lifelong bathing schedule. Did they take a shower first thing in the morning or right before bed? Did they prefer a shower or a bath? Try to maintain this routine during their illness.
 - Make sure the room is warm.
 - Use a hand-held shower wand to prevent getting water into the person's eyes.
 - Use a shower chair to avoid falls and the discomfort of standing.
 - If taking a bath, consider adding bubble bath, scents, and creating a "spa-like" pleasant experience that becomes a treat rather than a chore for your person.

- Allow your person to bathe with their underwear on. Your person may be modest about disrobing.
- Utilize distraction to reduce the stress of bathing (e.g., music or even eating a treat during the bath).
- If they refuse, take a break and try again later.
- Consider using baby wipes and dry shampoos to extend the time between baths or showers.
- Consider bathing in the sink with no-rinse soap.

“Why Is He Hiding Things and Accusing Me or Others of Stealing?”

- A common symptom of dementia is a fear of theft, resulting in the person with dementia hiding items. There is no way to prevent these incidents, but there are ways to minimize the loss of valuables.
 - Remove valuables from the house whenever possible.
 - Place jewelry not used daily in a safe or safety deposit box.
 - Put “clappers” or electronic beepers on house and car keys.
 - Learn your person’s hiding places. Some typical locations include:

♦ Under the mattress	♦ In food containers
♦ In the pages of a book	♦ In the freezer
♦ In curtain hems	♦ In the trash
♦ Under pillows	♦ Wadded in tissues in toilet paper rolls
♦ In back of pictures or mirrors	♦ In breakfront cabinets

As you see from the above conversations, care of people with dementia can be made more complicated than necessary. Insisting on telling the truth at all times or trying to “re-orient” the person can lead to conflict and agitation. Instead of focusing on the truth, think about how to improve your person’s emotional comfort. The difficult conversations will become easier.

SECTION FOUR— Care Issues as the Disease Progresses

Becoming a Caregiver

When someone develops a dementing illness, the disease affects everyone in the family and their constellation of friends. Those who become the primary care partner and provide direct care and are undoubtedly the most dramatically affected. The primary care partner becomes the co-pilot for the care recipient. Caregiving is a very complex activity: draining yet rewarding, demanding yet fulfilling, boring yet challenging, and intimate yet lonely. The direct-care providers often have to adjust their lives to accommodate a second set of schedules and needs, which are beyond the control of the person with dementia.

Caregivers come to their role in a variety of ways. They may be a spouse, adult child, or have a long relationship with the care recipient. The role may not have been accepted voluntarily. It is important to understand how and why the person was selected for the role, how it is being carried out, and what it is doing for the relationship. Are there any concerns about abuse, neglect, financial exploitation, or other mistreatment? Any suspicions of mistreatment should be reported or investigated by the local authorities, usually the State Department of Human Services.

Accepting Help

Caring for a person with dementia is best done by a team. At a minimum, the team should include family members, a physician, and health and social services professionals. As the person's care becomes more complex, additional professionals may be added. They may include physical and occupational therapists, speech pathologists, nutritionists, subspecialty physicians, psychiatrists, and psychologists. The number of team members depends on the person's medical condition, functional level, and behavioral profile.

There are several aspects of care that are particularly challenging. First, dementing illnesses are characterized by progression and ever-changing care needs. In most disabling conditions, care is focused on assisting with activities of daily living, including bathing, dressing, eating, toileting, and mobility. After these are accomplished, people requiring care are generally able to determine what activities they prefer for the rest of the day. When dementia is the primary concern, care of the recipient becomes increasingly dependent on determining what activities should be used to fill the day, whether the person's increasing disability has increased the risk of injury, and how to schedule them in a way that does not trigger late-day agitation. The care partner must balance his or her needs with the responsibilities required for care of the person with dementia. This balance involves addressing four issues:

1. Controlling what you can about the illness or condition
2. Letting go and not wasting your time and energy trying to control things that are not controllable
3. Focusing on finding solutions toward making realistic changes
4. Asking for and ACCEPTING help

It is important to keep a journal to record (and remember) your goals, strategies, and success as a caregiver. The journal need not be complex but should document strategies for care and your response to your efforts. It is a good place to record problems, medical conditions, troublesome behaviors, and the progression of impairment caused by the illness.

First, on an average-to-good day, list three things you like best about caring for your person with dementia. Include statements about how you feel about the work you are doing, positive responses from your care recipient and others, and self-value for the job you are doing. Examples might include: *"I can express my love through care."* Or, *"I am amazed at how much I accomplish each day."* Rank each statement on a scale of one to five with one as the least important and five as the most important to you.

Second, on an average-to-bad day, list three things you dislike about caring for the person with dementia. Rank these statements from one to five, with five being the most disliked activity. Now evaluate. Do the likes and dislikes balance out? If not, where would you accept help to feel more fulfilled?

Third, compose a checklist (Table 6) of tasks that you would be willing to give up (and to whom) and those you would be willing to keep.

Table 6. Task Delegation Checklist

Task	Delegate	Keep	N/A
Managing finances			
Paying bills			
Driving, providing transportation			
Planning all activities			
Yardwork			
Setting limits (driving, credit cards)			
Laundry			
Grocery shopping			
Supervising/giving medications			
Planning activities, keeping the person busy			
Other			

Once the check list is complete, you now know what tasks you would be willing to relinquish and to whom. You might delegate tasks such as yard work to a relative or hire a gardener. In your plan, you want to determine **what** you are going to do, **when** you plan to do it, and **how often** you plan to do it.

Even when the person is admitted to a residential setting, caregivers must supervise and monitor care and continuously balance expectations with the realities of long-term care environments. After residential placement, families must continue to provide certain aspects of care and advocate for their person's needs.

Taking Care of Yourself

As most caregivers take on the role of caring for someone with dementia, they frequently forget to take care of themselves in the process. With the vast demands on caregivers, little time remains for oneself. However, it is important to remember that if you don't take care of yourself, you will not be able to care for your loved one. Make time for yourself, your wellbeing, and the activities you enjoy (Table 7).

Table 7. Caring for the Caregiver

Manage Your Health	<ul style="list-style-type: none">• Get annual health screens and immunizations• Get adequate rest• Eat right and stay hydrated• Exercise 20 minutes at least 3 times a week
Watch for Depression	<ul style="list-style-type: none">• Feelings of guilt, grief, and ambiguous loss are common among caregivers, and unfortunately, so is depression• If you experience low mood, hopelessness, changes in appetite, changes in sleep patterns, irritability, difficulty with concentration, anxiety, loss of interest, or unexplained aches and pains, contact your doctor
Don't Forget to Take Time for Yourself	<ul style="list-style-type: none">• Use respite services: friends, family, paid caregivers• Get out with friends on a regular basis• Take time to attend to your spiritual or religious needs• Splurge on something that makes you happy
Don't Go It Alone	<ul style="list-style-type: none">• Attend a support group• Speaking with others who are going through similar experiences can be an invaluable resource• Support groups can also be a resource for making new friends and social contacts

Finding Help from Family

The Alzheimer's Association (2019) reports more than 80% of caregivers experience high levels of stress and almost half experience depression. Caregiving spouses between the ages of 66 and 96 who experience emotional strain have a 63% higher risk of dying than same-age non-caregiving peers. Accepting help and services is a way to help family direct-care providers to maintain their health.

The primary source of long-term care in America is the family, often adult children. This situation has its share of problems. Many adult children live across the country, or even out of the country, thereby removing access. Other issues that preclude adult children from participating in care are as follows:

- Being too busy with their lives and families to offer care
- Fear of dementia, whether fearing symptoms, violence, or inheriting the disease
- Fear of being rejected by the person with dementia
- Conflict or potential conflict about how the disease should be managed and the care provided
- Not wishing to be included in plans for residential placement or driving cessation
- Fear that participating in care might threaten a job or marriage

- Fear of traumatizing grandchildren by exposing them to someone who is “crazy” or “not normal”
- Fear of being asked to provide more care than they can handle
- Fear they will be asked to put the person with dementia in a nursing home
- Fear of being disinherited

Most of these fears and issues can be addressed by members of the care team working with the family over a period of months or years. However, it is important for you as the caregiver to be vocal about your need for help. Caregivers frequently see this need as selfish or demanding, but it is not. Family members may want to help but may not know *what* they can do to help. Family members must be asked for help and then told how they can help.

Hiring In-home Help

When hiring a caregiver, consider several factors. First, what type of assistance do you need with your person (housekeeping, personal care and grooming, companionship, meal preparation, transportation)? How much can you afford to pay? There are generally three options for in-home care:

1. Home care agencies

- Typically, the most expensive option, but they will prescreen, background check, and train caregivers
- Can provide consistent coverage even if a paid caregiver is sick

2. Private caregiver

- Less expensive option
- May be found by talking to family, friends, church, or support group
- Prepare a job description outlining your person’s needs. During the interview, determine if the caregiver has any limitations that may affect these duties or responsibilities, such as not being able to drive).
- Ask if they have appropriate experience and training, such as CPR training and dementia care training
- Conduct an online background check, with their written consent (try www.ussearch.com)

3. Volunteers

- Least expensive option – most appropriate in the early stages of illness
- Most volunteers provide limited support
- May be found by talking to in-faith communities. Try posting a request for a volunteer on a parish bulletin board or speaking with the parish nurse.
- Family and friends are another good resource. Be sure to ask them.

Adult Day Programs

Adult day health care programs are a wonderful resource of planned programs and activities for people with dementia. They provide the person with dementia an opportunity to get out of the house. These programs incorporate physical, social, and cognitive activities that help stimulate the person’s mind and body while enriching their quality of life. Adult day health care programs reduce social isolation and

provide a safe and structured environment for those who can no longer be left home alone during the day. They also provide much-needed respite for the caregiver.

It is not unusual for a person with dementia to refuse to go to an adult day health care program. Remember that this action requires them to change their routine and adapting to change in dementia is hard. Expect that they will be reluctant or even resistant to attending. Several strategies can be used to overcome this reluctance.

- Do not refer to the program as “day care.” Instead, present it as a “social club” or “physical therapy for the brain” prescribed by their doctor.
- If your person enjoyed helping others in the past, present this activity as a volunteer opportunity in which they can help others. Speak to the adult day health care staff about creating “tasks” for your person to perform at the facility (e.g., setting up plates, arranging flowers, keeping another resident company).
- Attend the first few sessions with your person and allow them to settle into the new routine with you there. As they become engaged in a particular activity, you may be able to slip away.
- Remember that it takes time to settle into a new routine.

Assisted Living and Memory Care

Options for residential care include assisted living facilities. Assisted living facilities can include:

- **Adult foster care homes:** Provide care for up to four people in the home in which the caregiver lives
- **Assisted living homes:** Individual homes care for up to 10 people
- **Assisted living centers:** Larger facilities that provide care for more than 10 individuals

Not all assisted living facilities are designated “memory care” or “directed care,” which requires additional qualifications and certification. As you consider an assisted living facility, consider that your person will require increasing levels of care as their disease progresses. A facility that provides various levels of care including memory care, which they can move into seamlessly as their needs increase, allows for the least disruptive environment.



The Arizona Department of Health Services Office of Assisted Living Licensing regulates and monitors these facilities. Additional information can be found on their website www.azdhs.org. You can also check the status of complaints against a facility at www.azcarecheck.com.

How to Make the Move to Assisted Living

As with all life transitions, mindful and methodical preparation is the key to minimizing mental and emotional stress. Selecting an assisted living center that specializes in memory care will provide the support you need throughout the move.

- **Start the Conversation Early (Depending on the Stage of Memory Loss)**

If possible, begin making the long-term care plan as early as possible after the dementia diagnosis. If your person is in the beginning stages of dementia, looking ahead to find the right community allows them to be a part of the process, which can make for a smoother transition when moving day arrives.

Ideally, the time to move to a community is when he or she is no longer able to live safely and independently at home or when the level of care required becomes more than what you and/or other caregivers are able to provide from a time and safety perspective.

On the flip side, if your loved one has mid- to late-stage disease, it can be upsetting to engage them in selecting a community and planning for the move. In some cases, it is better to wait until the change is imminent to announce the move. Enlist the help of family and friends for decision-making, sorting, and packing.



- **Choose a Community Specializing in Memory Care**

Not all assisted living communities are created equal, and many of them aren't equipped to care for residents with dementia. Moving is challenging enough, and the last thing you want to do is have to move your person a second time unless you absolutely must, so it is important to select the right community specializing in memory care (Table 8).

Table 8. Questions to Ask a Facility

Staffing
<ul style="list-style-type: none"> • Do you have a medical director on staff? • Are there RNs or LPNs on staff? If so, how many? Are they on-site 24/7? • What is the staffing ratio for each shift? • What medical services are available? (labs, X-ray, PT/OT/SP therapy, home health, hospice, podiatry, pharmacy) • What types of training does the staff have?
Policies and Fees
<ul style="list-style-type: none"> • Can my loved one stay here through the end of life, or do they have to move if their care becomes too extensive? • What types of care can your community NOT provide? • What is the policy for a medical emergency or ER visit? • Does a staff member go with the resident to the ER? • What is the policy for notifying family members? • What is the discharge policy? • Is the community all-inclusive, or are there additional costs? • What are the additional costs (i.e., cable television, phone, medication fees, care level fees, activities or outings, transportation)? • Can my loved one come back if they have to go to rehab? • What happens if my loved one is no longer ambulatory?
Amenities and Outings
<ul style="list-style-type: none"> • What are the daily activities like? How many days per week? • Do you charge for outside activities? (lunch outings, museums, etc.) • Do you have semi-private and private rooms? If cost is of concern, semi-private rooms can save residents thousands of dollars per year. • Which memory care community makes you feel the safest, most comfortable, and most secure?

- **Consider Visiting the New Assisted Living Community Together Before Moving Day**

Familiarity is key to feeling safe. Once a community is selected, some people find visiting the community a few times before moving day helps ease the transition. You and your person may consider attending and participating in activities and events, meeting other residents with similar interests, and interacting with staff. Each of these visits proactively builds layers of familiarity.

- **Schedule the Move for Their “Best Time of the Day”**

Typically, late mornings and early afternoons are a dementia patient’s “best time of the day.” Early mornings and evenings may be more difficult. The transition from one home to the next will be less stressful when your person is most likely to be calm, allowing more time to settle in before he or she becomes fatigued or agitated.

- **Bring a Simple Collection of Favorite Things**

Odds are their new room is smaller than their current home, and clutter is a recipe for confusion and trip hazards. If you haven’t received information from the assisted living community director or staff about what to bring from home, give them a call to find out how much is “just enough” to bring.

In some communities, rooms come furnished, but you should still be able to bring touches from home, such as a favorite chair, wall art, personalized bedding, and a CD player or iPod/docking station to play your person’s favorite music.

Having familiar pieces from home helps new residents settle in more quickly. And again, be careful about asking your person, *“Which items do you want to take with you?”* as these types of decisions can be agitating in later stages of the disease.

- **Communicate with the New Caregiving Staff**

First and foremost, the staff wants to get to know new residents. The more the new caregivers know about your person, the easier it is to spark conversations and connect with them as they settle in.

Additionally, it’s helpful to lean on the staff and allow them to explain the new transition and to support your person during the move. Again, choosing a memory care-specific community means the administration and staff are well-versed experts and know what to say without causing further confusion or upset for your person.

SECTION FIVE— Finding Help: Dementia Resources and Organizations

Local and National Alzheimer's Disease and Related Dementias Resources

Barrow Neurological Institute **602-406-4921**

240 W Thomas Rd, Ste 310, Phoenix, AZ 85013
www.barrowneuro.org/memory

Alzheimer's Association (National) **800-272-3900 - 24 Hour Helpline** www.alz.org

Alzheimer's Association (Desert Southwest Chapter) **602-528-0545** www.alz.org/dsw

Alzheimer's Disease Education and Referral Center **800-438-4380**

www.nia.nih.gov/alzheimers
Provides current, comprehensive Alzheimer's disease information and resources from the National Institute on Aging

Area Agencies on Aging - Maricopa County/Phoenix Office

602-264-2250
888-783-7500
602-264-4357 – 24 Hour Senior Helpline
www.aaaphx.org/

Provides information and referral for services for seniors by county that includes home-delivered meals and sources for caregiver respite

Arizona Department of Health Services **602-364-2690**

www.azdhs.gov
Regulates and monitors assisted living and skilled nursing facilities in Arizona. Find facility surveys

Arizona Department of Insurance **602-364-2499 - Phoenix Area** **800-325-2548 - Statewide**

www.id.state.az.us

Provides consumer assistance with insurance questions in addition to information on Medicare, Medicare supplement plans, long term care insurance, and AHCCCS/ALTCS.

Arizona Department of Transportation, Motor Vehicles Division **877-692-9227**

www.azdot.gov/MVD

Provides forms to apply for disabled parking plate and to report concerns about driving using Driver Condition Behavior Report Form

Association for Frontotemporal Degeneration **866-507-7222**

www.theaftd.org

Provides disease-specific information and help for those with frontotemporal diseases

Helpline: Leave a message, and someone will get back to you, generally within 24 hours on a weekday

Centers for Medicare and Medicaid Services (CMS)

800-Medicare (800-633-4227)

www.medicare.gov/nursinghomecompare
Offers a way to compare hospitals, nursing homes, and home care services on its website

Eldercare Locator **800-677-1116**

www.seldercare.acl.gov

National program that can help you locate a range of services in your area, including respite for caregivers.

Family Caregiving Alliance**800-445-8106**www.caregiver.org

Provides extensive caregiver resources.

Lewy Body Dementia Association, Inc**800-539-9767**www.lbda.org**MedicAlert Foundation International****800-432-5378**www.medicalert.org

Medical ID with paid 24-hour nationwide emergency response service for individuals with Alzheimer's or related dementia who wander or have a medical emergency

National Adult Day Services Association**877-745-1440**www.nadsa.org

Provides state by state help in finding local adult day care services

National Respite Locator Service**703-256-2084**www.respitelocator.org

Helps caregivers and professionals locate respite services in their communities

Northern Arizona Council of Governments**928-774-1895**www.nacog.org

Serves Apache, Coconino, Navajo, and Yavapai counties

Pinal-Gila Council for Senior Citizens**520-836-2758****800-293-9393**www.pgscsc.org**Dementia-Specific Products****Alzheimer's Store****800-752-3238**www.alzstore.com

Provides activity, caregiving, and safety products for all stages of Alzheimer's disease

Best Alzheimer's Products**877-300-3021**www.best-alzheimers-products.com

Provides ideas and products for caregiving that can be purchased online

Buck and Buck**800-458-0600**www.buckandbuck.com

Adaptive clothing for people with dementia or disabilities; catalog available

Comfort Plus**888-656-8055**www.comfortplusonline.com

Incontinence, bathroom safety, and hygiene supplies

Spec-L Clothing Solutions**800-445-1981**www.clothingsolutions.com

Specialty designed apparel that is designed to discourage undressing.

SECTION SIX— References and Suggested Reading and Viewing Lists

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Suggested Reading List

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Hall, G. (1999). *As Memory Fades, the Caregiving Challenge Begins*. Iowa City: University of Iowa, revised 2002.

Hall, G., & Buckwalter, K. (1987). A conceptual model for planning and evaluating care of the client with Alzheimer's disease. *Archives of Psychiatric Nursing*, 1(6), 399-406.

Plassman, B. L., Langa, K. M., Fisher, G. G., Heeringa, S. G., Weir, D. R., Ofstedal, M. B., ...Wallace, R. B. (2007). Prevalence of dementia in the United States: the aging, demographics, and memory study. *Neuroepidemiology*, 29(1-2), 125-132. doi:10.1159/000109998

Sheehy, C., & Hall, G. R. (1998). Rethinking the obvious. A model for preventing constipation. *J Gerontol Nurs*, 24(3), 38-44. doi:10.3928/0098-9134-19980301-08

The Association for Frontotemporal Degeneration. (2014). Understanding FTD: An overview. Retrieved from <http://www.theaftd.org/understandingftd/ftd-overview>

Suggested Viewing List

Pines of Sarasota. (2010). Bathing a patient with dementia/Alzheimer's. Retrieved from <https://www.youtube.com/watch?v=lxwJgDg3bYU>

APPENDIX 1—

Signs to Watch For in People Who Live Alone or Who Are at High Risk

The following factors may indicate when it is no longer appropriate for a person with dementia to live alone or when, at a minimum, the person requires additional services.

Classification

- A = Emergent:** Immediate help/placement required. Only one factor needs to be present.
- B = Semi-emergent:** Not an immediate threat to safety or well-being. May wait a few weeks, but the need for in-home services or support is clear; may work toward placement. Increasing safety risk when two or more persons are present in the household.
- C = Non-emergent:** Consider additional help, especially when three or more persons are present in the household. Re-evaluate monthly.

Combined letters indicate that the ranking depends on reviewers' perception of severity.

Reported or Observed Conditions

Grade	Observed Conditions
A	<ul style="list-style-type: none"> ___ Weight loss of > 6 lb or 10% body weight in 6 months or loose clothing, evidence of wasting (protruding bones) ___ Florid (agitated) paranoia, hallucinations, delusions, suicidal thought, aggression ___ Weapons present, especially loaded ___ Evidence of misuse of appliances or equipment, evidence of fire ___ No food in house or rancid food ___ Falls (especially with long lie > 2 hr), evidence of injuries, unexplained bruises, evidence of substance use ___ Medication mistakes or poor care for potentially life-threatening/unstable conditions ___ Reports of self-neglect or dependent-adult abuse, founded or unfounded ___ Repeated emergency department visits, hospitalizations, physical complaints ___ Evidence of caregiver injury, domestic violence ___ Calls police or emergency services frequently ___ Wandering outside the home ___ Eviction notice served

Reported or Observed Conditions *continued*

Grade	Observed Conditions
A/B	<input type="checkbox"/> Malfunctioning plumbing, especially no water or toilet stoppage <input type="checkbox"/> Thermostat set inappropriately for weather conditions <input type="checkbox"/> Chronic anxiety, panic attacks, chronic worry, depression <input type="checkbox"/> Unsafe driving, refuses to stop driving <input type="checkbox"/> Law enforcement referred
B	<input type="checkbox"/> Poorly managed incontinence <input type="checkbox"/> Repeated calls to family or others asking what to do next or expressing concern about planned activities <input type="checkbox"/> Dirty or infested household that poses risk to health <input type="checkbox"/> Garbage accumulation <input type="checkbox"/> Food stored inappropriately (e.g., ice cream in closet) <input type="checkbox"/> Exploitation by neighbors, friends, relatives, others <input type="checkbox"/> Resists personal care for prolonged periods of time
B/C	<input type="checkbox"/> Client states "I need to move," "I can't take this much more," or otherwise indicates he/she feels a move is imminent <input type="checkbox"/> Neighbors and others complain of unwanted or unrealistic dependence on them <input type="checkbox"/> Phone calls from community members advising help is needed
C	<input type="checkbox"/> Vegetative or socially isolated behavior (sitting all day with TV on or off) <input type="checkbox"/> Missing belongings, hiding things <input type="checkbox"/> Poor grooming and wearing same clothing all the time, clothing is soiled <input type="checkbox"/> Post-it notes throughout house

Scores: **As**_____ **A/Bs**_____ **Bs**_____ **B/C**_____ **Cs**_____

Observation Cues

1. Outside the home

- What is the condition of the yard?
- Are the windows open or shut consistent with safety and the season?
- What is the condition of the home?
- Is the door locked or unlocked appropriately?
- How does the client answer the door?

2. Just Inside

- What is the temperature of the home?
- What is the general condition of interior?
- Client's appearance: Does the client have a body odor, grooming or absence of, stains on clothing, hair/shaving, absence of mouth care, appropriateness of clothing (shoes)?
- Are there any odors?
- Is the house cluttered or looking "unlived in"?
- Is there evidence of infestation?
- Does the client have pets and what is their condition?

3. Further Inside

- Does the client have stacks of papers, mail, evidence of overuse of scams?
- Is the house dusty and dirty?
- What are interactions with others like?
- Where does the client sleep?
- Is the furniture soiled?
- Is the television on?
- Condition of the bathroom:
 - Is the plumbing clean?
 - Does the plumbing work?
 - Are medications present?
- Condition of the bedroom:
 - Are the linens clean?
 - Is clothing orderly?

4. Kitchen

- Is it clean or infested?
- Is there evidence of cooking or eating?
- Is it stocked with food?
- Does the refrigerator contain food or mold?

5. Listening

- Does what the client says fit with what you see?
- What are the client's social skills like?
- Is telephone use during the day an appropriate amount or repetitive?

Living Alone Checklist is used with permission from University of Iowa, College of Nursing.

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THANK YOU

Thank you to the following individuals and organizations that are supporting our efforts to end Alzheimer's disease, while caring for all those who are currently suffering its effects.

Julia and George Argyros
Arizona Alzheimer's Consortium
The Barrow Women's Board
The Board of Visitors
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Ann and Gregory P. Denk
The Edward Fein Trust
Global Alzheimer's Platform
Diane and Bruce Halle Foundation
Hanley Living Trust
William K. Heinlein and Ann Heinlein Revocable Trust
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Jack and Heidi Rasor
The Steele Foundation
The Surplus Line Association Of Arizona Foundation in memory of Marian Silver
James T. and Traci L. Swanson
Carol Warstler

For more information on how to support the Alzheimer's and Memory Disorders Division contact the Barrow Neurological Foundation.

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