

NAVIGATING THROUGH MEMORY LOSS & DEMENTIA



A Guide for Patients & Families



NAVIGATING THROUGH MEMORY LOSS & DEMENTIA

This handbook was created as a guide for families who have basic questions about memory loss and dementia. Hilltop is dedicated to helping families whose loved one has dementia by providing a full spectrum of services and living options in our community.

For free advice and guidance on dementia call:
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This booklet available online at
seniordaybreak.org, under resources

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Table of Contents

GETTING STARTED: GETTING A DIAGNOSIS

What should a person do if concerned about a loved one's memory and behaviors?	1
Does one really need to get a diagnosis?	1-2
How does one know which physician or practice to go to for a diagnosis?	2
What exactly is dementia?	2
What kind of physician should one go to for a diagnosis?	3
TABLE 1: EARLY WARNING SIGNS OF DEMENTIA	3-5
TABLE 2: CONDITIONS THAT CAUSE DEMENTIA	5
How is a diagnosis made?	6
What does it mean if the diagnosis is "dementia from probable Alzheimer's disease?"	6
What does it mean if the diagnosis is "mild cognitive impairment?"	7
What does it mean if the diagnosis is "dementia from unknown cause?"	7
What should one do if the diagnosis is "nothing to worry about...just normal memory loss due to aging" but one feels there is more to worry about?	7
What should one do if they can't get the person to go to a physician?	7
Does a person know they have dementia?	8
Should the person be told that they have a diagnosis of dementia?	8
What should one do if concerned about someone who is not their family member?	8

MANAGING & UNDERSTANDING THE DEMENTIA

Can a person diagnosed with dementia continue to take care of themselves & manage their own life?	9
What kind of medical treatment options are available?	9
Are all dementias treated the same?	10
What can one do to best manage the dementia?	10
Should one tell other family members and friends, neighbors, and coworkers about the dementia?	10
How does dementia progress?	10

Table of Contents

PLANNING & PREPARATION

What kind of planning and preparation needs to be done once a person is diagnosed with some type of dementia?	11
How much time does one have to plan and prepare?	11
What kind of legal arrangements/documents need to be made?	11-12
What kind of financial arrangements need to be made?	12
Does medical health insurance pay for different types of dementia care?	13
What is Medicare and what will it pay for?	13
What is Medicaid and what will it pay for?	13-14
Will the Veterans Administration pay for dementia care?	15
Should a person diagnosed with dementia apply for long term care insurance?	15
What kind of medical planning needs to be done?	16
What kind of living arrangements need to be considered?	16
How does one know when it is no longer safe for the person with dementia to live alone?	17
How does a family convince a person with dementia to move out of their own home?	17
If the person with Dementia needs to be replaced in a care facility, what determines whether they need assisted living or nursing home care?	17-18

DEMENTIA FROM ALZHEIMER'S DISEASE

How does one best care for a loved one with Alzheimer's disease or other types of Dementia?	19
What does "early stage" Alzheimer's disease look like?	20
What does "middle stage" Alzheimer's disease look like?	20
What does "late stage" Alzheimer's disease look like?	21
Does everyone with Alzheimer's disease exhibit challenging and irritating behaviors?	21
Does everyone with Alzheimer's turn mean and aggressive from the dementia?	21
Can Alzheimer's disease be prevented or stopped from getting worse if one has already been diagnosed?	22
If someone has Alzheimer's disease will their children get it?	22

Table of Contents

CAREGIVER SUPPORT

Who is the best person to be the caregiver of a person diagnosed with dementia?	23
What kinds of skills will a caregiver need?	23
What type of help might a caregiver need?	23
Where can a family go for dementia support?	24
Dementia resources & advice	24

MEMORY CARE + SENIOR LIVING COMMUNITIES 25-26



Getting Started

Getting a Diagnosis

What should a person do if they are concerned about their loved one's memory and behaviors?

- Make a written list of all the things that the person you are worried about has done or said, related to their memory or behavior, that is the cause of concern. Review the early warning signs of dementia in Table 1 (see page 3) and check those that match your list. If you have check marks in 3 or more categories, and especially problems with short term memory, make an appointment with a physician.
- Fax your list of concerns ahead of time for the physician to review before the appointment. During the appointment, be sensitive to the feelings of the person you are concerned about when talking about them, in front of them, to the physician.
- If you are worried about yourself, have a close relative or friend make and compare the list for you. It is sometimes difficult in the early stages of dementia to tell if problems are just normal memory loss from aging or truly dementia.

Does one really need a get a diagnosis?

- Yes, it is recommended. Many conditions can cause memory loss and confusion. Some of these conditions once treated can stop or improve the memory loss. It is important to diagnose the cause so proper treatment and management can take place. Early diagnosis allows the person to partake in planning and preparing for the future while still able.

- May exhibit bizarre or eccentric behaviors that they have never shown before
- May become extremely suspicious, fearful, or paranoid
- May say or do embarrassing things (social graces become compromised)
- May have an inappropriate emotional response to a situation

Loss of Motivation & Initiative

- May have difficulty entertaining themselves by thinking of activities to do
- May have difficulty planning and executing projects or events
- May become very unmotivated and unwilling to do much other than sit and stare or watch TV
- May sleep more than usual
- May have no desire to do activities or hobbies that they used to do
- May say they don't feel good to avoid doing activities

How does one know which physician or practice to go to for diagnosis?

There is no one clinic that specializes in diagnosing dementia in Grand Junction at this time, but there are many physicians who are knowledgeable and who have patients with dementia. Start with your primary care physician since he/she knows you best. Ask them about their experience in diagnosing dementia. Make an appointment if you are comfortable and have confidence in them. He/she may do all the tests and then diagnose, or may do part of the tests then send you or your loved one to a neurologist for further testing. There are several clinics in the Denver area that do specialize in the diagnosis of brain illness. The Banner Alzheimer's Institute in Phoenix, Arizona specializes in dementia diagnosis.

What exactly is dementia?

The word "dementia" describes a broad category of illnesses that affect the brain. It is not a specific disease. It is a broad word like "cancer", and like cancer, there are many types of dementia. Dementia is a word that describes the symptoms of:

1. Loss in ability to think, learn, and remember
2. Personality changes

What kind of physician should one go to for a diagnosis?

A Neurologist, a Neuropsychologist, or physicians who specialize in Internal Medicine, Family Medicine, or Geriatrics can all diagnose memory problems and dementia.

TABLE 1: EARLY WARNING SIGNS OF DEMENTIA

Short term memory loss that affects daily life

- May repeat stories or questions
- May forget appointments
- May have difficulty recalling recent events, such as what they ate for breakfast or who they talked to on the phone earlier in the day
- May have difficulty remembering & taking medications
- May have difficulty learning new things

Difficulty performing familiar tasks

- May neglect or forget how to perform usual routine chores such as cooking and laundry
- May neglect or forget about housekeeping, allowing food to spoil and clutter to overwhelm
- May hoard food and other items
- May ruin household tools or equipment such as a blender or lawn mower by taking them apart “to fix” or using them inappropriately
- May neglect or overfeed a pet

Problems with language and conversation

- May have trouble finding the right word
- May have trouble keeping up with a conversation
- May respond inappropriately to a conversation
- May have difficulty reading or spelling

Disorientation to time and place

- May have confusion about what day of the week, month, season, or year it is
- May have confusion of where they are and how they got there
- May get lost driving to familiar places, including finding their way home
- May get lost in shopping malls or stores

Poor or decreased judgment

- May become vulnerable to scams
- May choose inappropriate clothing for the weather
- May have difficulty making judgments about their own safety
- May have difficulty making decisions, and may make some decisions without any regard for consequences

Problems with numbers and money

- May have trouble balancing their check book, paying bills, or getting change
- May withdraw large sums of money from the bank and lose it
- May give away large sums of money to relatives, strangers, telemarketers or be easily suckered by scams
- May spend large amounts of money on items they already have or don't need

Misplacing things

- May constantly search and even obsess over misplaced items such as keys, purse, wallet, or jewelry
- May put things in unusual places like jewelry in the sugar bowl or a dirty coffee cup in a dresser drawer

Problems with hygiene

- May stop bathing and grooming appropriately
- May wear the same item of clothing day after day even when it is obviously soiled
- May neglect dental care

Changes in personality & behavior

- May become more aggressive, or more passive, or just different from how they've always been

TABLE 2: CONDITIONS THAT CAUSE DEMENTIA

3. A slow progressive decline in the person's ability to perform tasks

- Alzheimer's Disease (leading cause of dementia)
- Vascular dementia (series of small strokes)
- Parkinson's disease
- Frontotemporal dementia (Pick's disease)
- Physical injury to the brain
- Huntington's disease
- Creutzfeldt-Jakob disease (mad cow disease)
- Severe liver or kidney disease
- Severe alcohol abuse
- Encephelitis
- Brain Tumor*
- Hydrocephalus*
- Depression*
- Medication side effects*
- Thyroid problems*
- Poor diet*

4. A diminishing ability to tolerate stress

Dementia is not a normal part of aging and it is always caused by something. There are approximately 60 conditions that can cause symptoms of dementia. The most common type of dementia is Alzheimer's disease. Other types of dementia are Lewy Body Dementia, vascular dementia, frontotemporal dementia, dementia from Parkinson's disease, and dementia from depression, to name a few. See Table 2 for a list of other dementia causing conditions and diseases.

**The conditions that cause dementia that are marked with an asterisk may be reversible or treatable. Persons with symptoms of dementia should see their doctor in case their symptoms of dementia are caused by one of these conditions.*

How is a diagnosis made?

Diagnosis of dementia is made after a series of tests and procedures are performed. These include:

- 1) obtaining a verbal or written history of concerns, symptoms and behaviors from the closest family member (the actual patient is not considered reliable for history and symptom accuracy).
- 2) blood tests (usually for thyroid and B12) and imaging tests (usually an MRI or CAT scan of the brain)
- 3) physical and neurological examination (the assessment of sensory neuron and motor responses, especially reflexes, to determine whether the nervous system is impaired)
- 4) cognitive examination (test of memory and thinking skills)
- 5) depression screening

The results of all tests and procedures are analyzed by the physician. A physician can almost always diagnose the presence of dementia. The actual cause of the dementia is sometimes difficult to determine.

What does it mean if the diagnosis is “dementia from probable Alzheimer’s disease”?

Alzheimer’s disease is a brain disease, cause unknown, and is the most common form of dementia accounting for up to 60% of all dementias. It is typically characterized by gradual onset of memory loss followed by a continued decline in other areas of mental, and eventually physical functioning. Common losses begin with difficulty in managing everyday activities, such as household affairs, followed by the ability to care for oneself. Communication abilities are lost over time, along with walking, bladder, and bowel control.

Alzheimer’s disease is actually a diagnosis based on the process of elimination where all other possible causes and diseases are gradually ruled out. Since there is no single definitive test for Alzheimer’s such as a blood test or brain scan (a new PET scan is being used in research settings but is not affordable or readily available to the public yet), the diagnosis usually includes the word “probable”.

What does it mean if the diagnosis is “mild cognitive impairment”?

Mild cognitive impairment is a term used to describe the subtle but notable changes in language, attention, reasoning, judgment, reading and writing, along with the complaint of memory problems. People with MCI carry out everyday activities without difficulty, therefore, they do not meet the full criteria for having dementia. 80% of people diagnosed with MCI will go on to develop dementia from Alzheimer’s disease, but 20% will not.

What does it mean if the diagnosis is “dementia from unknown cause”?

The doctor is unable to determine the cause of the dementia, and the symptoms and progression are not following the normal path of Alzheimer’s disease, or any of the other common dementias.

What should one do if the diagnosis is “nothing to worry about... just normal memory loss due to aging”, but one feels in their gut that there’s more to worry about?

Get a second opinion. Physicians do not know your loved one as well as you do. Plus, if a person does have dementia, the more time that goes by the more obvious the symptoms will become.

What should one do if they can’t get the person they are concerned about to go to a physician?

There is no easy answer to this and it can be a challenging ordeal. Coaxing and persuasion is sometimes necessary. Persistence and subtle tactics may have to be employed. An example of a subtle tactic might be telling the person that you are both going in for a memory screening because you are worried about yourself. Or, you might lead the person to believe that you are taking them to the doctor for a different health issue (and inform the doctor ahead of time that the real issue is cognitive concerns).

Does a person know that they have dementia?

Most people know that something is going wrong with their ability to think and remember. Some people appear to be oblivious. This will vary by the individual.

Should a person be told that they have a diagnosis of dementia?

Many physicians and professionals believe that each person has the right to know their own diagnosis so they can partake in plans for their own future. However, depending on the individual and their level of dementia, they may not remember when told, or the discussion of the subject may cause great anxiety. If this is the case, families should use their best judgment and knowledge of the individual with regards to discussing the diagnosis

What should one do if they are concerned about someone's memory and behaviors and that person is not their family member?

Caring, managing and planning for a person with dementia is a huge responsibility and one that cannot be taken lightly, as the person will need a lot of help and attention as the dementia progresses. All effort should be made to contact the closest relative and inform them of the situation and the need for their involvement. When there is no family member to contact, it is advised to call the Department of Human Services, Adult Protective Services. This government agency will assess the situation and if it is determined that this person is in self neglect, has been abused, or is a victim of a scam they will, with the person's permission, try to contact family and connect them to services and resources. In extreme cases, a court appointed guardian may be put in place if the person with dementia does not have anyone else to assume responsibility.

A professional care manager or Geriatric Care Manager could be involved, if the person is willing, and can do short term assessments or connect them to resources. There is generally a fee for this type of care management.

Managing & Understanding Dementia

Can a person diagnosed with dementia continue to take care of themselves and manage their own life?

A person with dementia, especially of the Alzheimer's type, will need increasing help and support as the dementia progresses. They will gradually be unable to take care of themselves and manage their own life. It is important to have a trusted "co-pilot" to help them navigate the complicated course of their disease. This co-pilot can be a spouse or life partner, an adult child, an adult grandchild, any relative, or a close friend.

What kind of medical treatment options are available?

There are currently FDA approved drugs that are used to treat dementia from Alzheimer's. Drugs approved for the treatment of the progression of the disease are Donanemab (also known as Kisunla) and Lecanemab (Leqembi).

Drugs approved for treatment of cognitive symptoms are Benzgalantamine (Zunveyl), Donepezil (Aricept), Rivastigmine (Exelon), Galantamine (Razadyne), Memantine (Namenda), and Memantine + Donepezil (Namzaric). These drugs are believed to chemically boost a person's memory allowing them to retain independence for a longer period of time. One of these three drugs (Aricept, Exelon, or Razadyne) is often prescribed as standard procedure upon diagnosis, and often given in combination with the fourth drug, Namenda. The effectiveness of these drugs varies from person to person. Some will benefit, others will not. Some will have an adverse reaction.

Drugs approved for non-cognitive symptoms (behavioral or psychological) are Brexpiprazole (Rexulti) used to treat agitation and Suvorexant (Belsomra) which is used to treat insomnia.

Other dementias besides Alzheimer's are sometimes treated with these drugs, too, in combination with other drugs specific to the condition. Medications for mood are sometimes prescribed to manage psychiatric and/or behavioral symptoms that may occur sometime during the course of the diseases.

Are all dementias treated the same?

No, people with different types of dementia have different care needs. There are similarities with different types of dementia, though, and sometimes people have dementia from two or more different causes. Some types of dementia have better treatment options than others.

What can one do to best manage dementia?

Managing any type of dementia is the same as managing any kind of chronic disease. It is important to discuss options and choices with loved ones. Choosing a healthy lifestyle with nutrition, exercise, and adequate sleep are critical with any type of chronic disease. Choosing to stay mentally, socially, and spiritually active are also important decisions. Planning and preparing for the future as the dementia progresses is crucial. Being proactive can help you from becoming reactive when the time comes for next steps.

Should I tell other family members and friends, neighbors, and coworkers about the dementia?

The choice to tell, or not to tell, is a personal one. Usually by the time dementia has been diagnosed, close family and friends have already noticed the difficulties and changes that have occurred with memory and behavior. Apprising them of the situation usually invokes their desire to help and be supportive. Building a support team for you and your loved one can help to decrease your stress level as primary caregiver.

How does dementia progress?

Every person with dementia is very different and unique and will progress at different rates. Individuals may have other conditions to factor in such as heart disease or cancer. Dementia from Alzheimer's disease is usually a gradual progression/decline over the course of 8-12 years. It is impossible to predict how a person's dementia will progress.

Dementia does attack the brain asymmetrically. Most of the time it attacks the left side first which is where language comprehension and speech production is. This may impact your loved ones ability to understand what you are saying to them and their ability to respond.

Planning & Preparation

What kind of planning and preparation needs to be done once a person is diagnosed with some type of dementia?

Much planning and preparation needs to be done after a diagnosis of dementia in the following areas: legal, financial, medical, safety, living arrangements, and caregiver support such as respite or attending support groups.

How much time does one have to plan and prepare?

It depends on the type of dementia, but usually the sooner plans are discussed the better, to allow the person with dementia to partake while they are still able.

What kind of legal arrangements/documents need to be made?

It is important for a person with dementia and their family to discuss their health care and financial arrangements. This is called Advance Planning.

A person with dementia will need to appoint a trusted family member or significant friend to be their health care proxy for when they are unable to make health care and financial decisions on their own. The earlier this is done the better, as the person must still have the mental capacity to appoint someone and make decisions.

The following legal/medical documents should be completed by the person with dementia and their family: Living Will, Durable Power of Attorney for Health Care, CPR Directive (cardiopulmonary resuscitation), and Organ Donation (optional).

The following legal/financial documents should be completed by the person with dementia and their family: Will, Durable Power of Attorney for Finances, Living Trust. ¶

These documents can be found on the Internet, in an office supply store, or drawn up by an attorney. You do not have to hire an attorney to draw up these documents, however, it's important to understand that laws vary by state and these documents can be confusing. Changes in situation such as divorce, relocation, or a death in the family can also influence how the documents are prepared and subsequently maintained. If there is the potential for disagreement or conflict between family members regarding the person with dementia's care, it is advisable to use an elder law attorney to ensure that the person with dementia's wishes are upheld and protected.

If the person is too far advanced with the dementia and does not have the capacity to make decisions and complete documents, obtaining guardianship (a person appointed to manage medical decisions) & conservatorship (a person appointed to manage financial decisions) from the courts is the only option. This process is lengthy and complicated. If possible, avoiding this by discussing choices and plans and preparing documents early is advised. None of these documents will do the person with dementia and their family any good if no one knows about them. Share these documents with key family members, and place original documents where they will be safe and secure and readily available when needed.

What kind of financial arrangements need to be made?

Caring for a person with dementia, or any chronic illness for that matter, can get very costly. It is important to assess one's financial situation and make plans for how one is able to pay for care. Sources for paying for care can include private pay, long term care insurance, veterans benefits, and Medicaid. Expenses that may occur include: physician or hospital bills, medications, medical equipment (i.e. wheelchair, walker), personal care supplies (i.e. depends), home health care assistance, respite assistance (i.e. attending a specialized Adult Day Center), placement in assisted living care facility, or placement in nursing home care facility.

Does medical health insurance pay for different types of dementia care?

Regular medical health insurance will usually only cover standard doctor visits and acute illnesses. This type of medical insurance will not pay for home health care, a specialized adult day center, or long term placement in an assisted living or nursing home.

What is Medicare and what will it pay for?

Medicare is the federal program primarily for older adults who contributed to Social Security and Medicare while they were employed.

Medicare will pay for nursing home services for 20 to 100 days for individuals who require skilled nursing care or rehabilitation services following a hospitalization of at least three consecutive days. To be eligible for a Medicare covered skilled nursing facility care, a physician must certify that the individual needs daily skilled nursing care or other skilled rehabilitation services that are related to the hospitalization.

Medicare does not pay for long term placement in an assisted living care facility or nursing home. Medicare does not pay for a adult day center. Medicare will pay for home health care under acute medical situations for up to 60 days, but will not pay for ongoing long term home health care.

What is Medicaid and what will it pay for?

Medicaid is a federal program implemented with each state to provide health care and related services to those who's income bracket is within "poverty level". Each state defines poverty, and therefore, Medicaid eligibility. Those eligible for Medicaid may be aged, disabled, or children.

Medicaid offers assistance in paying for in-home care, specialized adult day center, assisted living care and nursing home care (plus many other programs including electronic monitoring, non-medical transportation, home modifications, community transition services, and medication reminder units). To qualify for Medicaid benefits recipients must meet criteria in three areas: medical condition, income, and financial resources. ¶

- **MEDICAL CONDITION:** Must have significant problems with activities of daily living such as eating, bathing, transferring, mobility, toileting, and the need for supervision. This is assessed on an individual basis by a Medicaid Case Manager. Those with dementia will most likely meet this criteria as it is expected that their abilities with activities of daily living will decline.
- **INCOME:** Individual Income limit is \$2,901/month*, and the applicant's spouse's income is not counted. For those not hospitalized, an income trust can be established if income exceeds the limit.
- **ASSETS/RESOURCES:** Individual applicant may have up to \$2,000* in assets/savings. If a couple, the community spouse may have up to \$157,920* in assets. Assets that are not counted include:
 - Personal possessions such as clothing, furniture, jewelry
 - One motor vehicle (regardless of value)
 - Principal residence
 - Prepaid funeral plans

Transferring assets to others within 5 years of the application will result in a penalty period. Spending down to reach qualification criteria is often done.

The Rocky Mountain Health Plans (RMHP) is the organization in Mesa County that runs the Medicaid program. To apply for Medicaid an individual must complete an application, attach appropriate documents showing proof of income, etc., and meet with eligibility specialists who will determine the individual's medical condition. Determining eligibility for Medicaid benefits usually takes about two-four months (in Mesa County). Rocky Mountain Health Plans, 970-243-7050.

Understanding the ever-changing rules and regulations for qualifying for Medicaid can be complicated. If a person clearly meets the criteria of all 3 areas, then applying directly with the Rock Mountain Health Plans is logical. If there is a spouse involved, with assets greater than the qualifying amount that could potentially be spent down, it is advisable to consult with an elder law attorney to plan ahead and strategize on how to best preserve assets for the community spouse.

**These numbers from 2025 and may change annually.*

Will the Veterans Administration pay for dementia care?

The Veterans Administration branches:

- Medical Centers for Health Care (Grand Junction is the smallest center in the country)
- Department of VA Benefits (Denver)

MEDICAL CENTERS: To receive medical care at the VA Medical Center a veteran must be enrolled in their system and complete an application for health benefits. This is an easy process which can usually be done quickly by meeting with one of the Social Workers and verifying records and dates of service on the computer. The Social Worker will determine what medical services and programs are appropriate for the veteran. Services can include dementia diagnosis, medical care, hospitalization, adult day care, skilled and non skilled home care, respite for the family, host home placement, nursing home placement, and hospice. The VA may cover all or part of the expenses. VA Medical Center, Grand Junction, 970-242-0731.
www.va.gov/western-colorado-care

VA BENEFITS: A wartime veteran, who has limited or no income, may qualify for a VA Pension and/or Aid & Attendance and Housebound Benefits. Qualification is based on specific criteria: honorable discharge, 90 days of active military service and at least 1 day was during a war time period, income below the maximum annual pension rate set by Congress, and age 65 or older or disabled or patient in nursing home or receiving social security disability benefits. A vet can complete an application online or contact the local Veterans Service Officer who will assist the individual with the application and submit it to the Department of VA Benefits in Denver. The process can take up to 18 months. Veterans Service Officer, VA Medical Center, 970-242-0731 ext. 2112

Should a person diagnosed with dementia apply for long term care insurance?

If a person is already diagnosed or showing signs of dementia, it is usually too late to obtain long term care insurance for them. However, spouses and other family members might want to consider this type of insurance in their own future planning.

What kind of medical planning needs to be done?

Finding a physician who is knowledgeable and experienced in caring for patients with dementia is important. The person with dementia will still have all of the same typical health issues for their age that everyone faces. With dementia, however, these issues are sometimes more difficult to notice and address due to the person's declining awareness of their own body. Families should prepare for any type of medical issue or emergency by establishing a primary physician, compiling an updated list of the patient's medications, a list of their prior medical issues/history, and complete advance planning documents discussed on page 11.

What kind of living arrangements need to be considered?

Persons with dementia will lose the ability to live alone. This is one of the biggest challenges a family will face. Balancing that person's independence with their safety is difficult. The person with dementia will need to live where others can oversee their safety, nutrition, medical needs, social activities, and finances. Options for living arrangements are:

- Living in their own home with their spouse or other relative
- Living in their own home with a paid professional caregiver
- Living in the home of their adult children or other relative
- Living in an assisted living or nursing home care facility

How does one know when it is no longer safe for the person with dementia to live alone?

A person with dementia should not live alone if they are showing any signs of unsafe behavior. Persons with dementia will lose the ability to stay out of harm's way. As the condition progresses, curiosity increases and safe awareness decreases. Keeping a person with dementia safe is a huge concern and requires constant vigilance. It is often a delicate balance to preserve the person's sense of independence, privacy, and dignity while keeping them safe.

Signs of unsafe behavior would be: taking medications improperly, not eating properly, spoiled food in the refrigerator that they believe is still good to consume, leaving stove on, improper use of or breaking household tools such as washing machine or microwave or lawnmower, wandering away from the house and getting lost, frequent trips and falls, and complaints by neighbors of inappropriate actions. Safety is a judgment call by the family. Living alone with dementia is an accident waiting to happen.

How does a family convince a person with dementia who lives alone to move out of their home?

There is no magic answer to this difficult dilemma and it can be very challenging and stressful. Most people with dementia will believe that they are still able to function and stay safely on their own. They may be extremely resistant to the idea of being uprooted from their home or moving in with their adult children or being placed in a care facility. Coaxing and persuasion along with persistence and subtle tactics will sometimes work. Most often, families must plan and execute the move despite resistance and hope their loved one adapts. This difficult situation invokes a lot of guilt, sadness, and anger, but is sometimes the only option when ensuring that a loved one receives the care and oversight that they need because of the dementia.

If the person with dementia needs to be placed in a care facility, what determines whether they need assisted living or nursing home care?

Each assisted living facility and nursing home facility is unique in their policies for accepting persons with dementia. They all assess potential residents on an individual basis, looking at the person's level and type of dementia, physical mobility, other health issues, and payment source. All facilities have the right to accept or not accept a person as a resident ¶

Assisted living facilities have residents that vary greatly in their need for assistance. Some residents are fairly independent, while others, especially those with dementia, require different amounts and types of assistance, usually with bathing, dressing, grooming, taking medications, preparing meals and toileting. Assisted living facilities often have a fee tier associated with the level of assistance needed. Each individual is assessed and a unique care plan is created for their special needs. This care plan is updated as changes occur with the resident.

Generally speaking, nursing homes are for people who require constant nursing care and have significant deficiencies with their abilities to eat, bathe, toilet, dress, take medications, and walk. These residents need a higher level of “skilled medical” nursing care. These facilities often provide physical, occupational, and other rehabilitative therapies following an accident or illness.

The potential for “wandering” is a huge factor in choosing a care facility. Each assisted living and nursing home is unique in their setup for handling wanderers. Person’s with dementia will commonly wander (walk away from their home or residence) and get lost. Some facilities are “secure” which means the whole facility, or a wing of the facility, has a locked door system preventing the resident from leaving at will. Some facilities use “Wander Guard”. This means they have a special alarm system installed, the resident wears a special bracelet, and if they go out the door the alarm is triggered by the bracelet alerting staff.

It is not always possible to predict who has the potential for wandering and who does not. This is why facilities will assess the person with dementia on an individual basis. A resident with dementia may start out living in the general population area of the facility, then as their dementia progresses they may move to an area or wing that offers a higher level of assistance (such as “Hope Harbor” in The Commons and “Companion Care” at the Fountains Assisted Living Facilities), and as their dementia progresses further they may then move to a secure wing of the facility that is especially designed for those with more advanced dementia (such as “Safe Haven” Memory Care at The Commons of Hilltop). Hilltop offers a “Continuum of Care” which means there are options for all levels of dementia care.

Some people with dementia are kept at home by their families throughout the entire journey, while others are placed in care facilities at varying stages of the illness. The decision to place or not to place relies with the primary caregiver (co-pilot). There are many variables that factor in: the emotional state of the co-pilot, the health of the co-pilot, the determination of the co-pilot, the amount and types of challenging behaviors the person with dementia is exhibiting, the physical mobility of the person with dementia and their propensity to wander, the financial situation, the physical layout of the home, the amount of help and support the co-pilot is receiving, and the opinions of other family members.

Dementia From Alzheimer's Disease

How does one best care for a loved one with Alzheimer's disease or other types of Dementia?

Learning everything one can about Alzheimer's disease and Dementia is the best way to understand and care for a person with this devastating disease. Knowledge is empowering. Knowing what lies ahead and being proactive about seeking out ways to get help will give the caregiver/co-pilot the best chance of coping and surviving. Understanding that living in the land of denial is not really an option is key. In a nutshell, here is what to expect:

- Your loved one's ability to think, remember, and take care of themselves will gradually diminish within a time span of 3-15 years. (The average life span after diagnosis is 8-10 years). Alzheimer's is eventually fatal, though many often die from something else first before the disease runs its slow insidious course.
- Your loved one will experience a lot of fear and confusion as a result of the disease and damage to their brain.
- Your loved one will repeat themselves constantly and will probably exhibit bizarre behaviors and changes in their personality that will surprise and/or sadden you, and require tremendous patience and understanding on your part.
- Your loved one will eventually become totally dependent on you and others and will gradually lose the ability to talk, walk, eat, dress, bathe, and toilet without assistance.
- Despite the devastation from this disease, you and your loved one will find many moments and opportunities during the course of the disease to share love and joy. Families often find strengths they never knew they had and forge new bonds with each other.

What does “early stage” Alzheimer’s disease and some types of Dementia look like?

- Difficulty with short-term memory
- Poor concentration
- Poor decision making
- Problems remembering the right word or name
- May become depressed or socially withdrawn
- Difficulty organizing and managing household affairs such as cleaning, cooking and yard work
- Trouble handling finances
- Difficulty initiating activities
- Gets lost/mixed up when driving in familiar places
- May be involved in “fender benders”

What does “middle stage” Alzheimer’s disease and some types of Dementia look like?

- Difficulty with short and long-term memory
- Forgets own personal history
- May begin to forget friends
- May not understand what is being said and/or unable to comprehend written materials
- Losing ability to express self and make needs known
- More easily upset and frustrated
- May appear to lack emotion
- Needs help with the following:

Dressing

- Selecting/coordinating clothing
- Putting clothes on in the right order
- Buttoning, zipping, snapping clothing

Grooming

- Lack of attention to fine details
- Needs reminders for shaving, brushing teeth
- Unable to apply make-up

Bathing

- Forgets to bathe
- May become afraid of water in bath/shower

Bladder & Bowel

- Difficulty finding the toilet
- Forgets to wipe and/or flush
- Incontinent episodes

Eating

- Forgets to eat or drink
- Forgets how to use silverware
- May lack table manners

What does “late stage” Alzheimer’s disease and other types of Dementia look like?

- Severely impaired memory for recent and past events
- Unable to carry on a meaningful conversation
- Appears withdrawn
- Difficult to engage
- Has difficulty interacting and responding to surroundings
- Forgets how to walk without help; may lead to eventual loss of body movement
- Relies totally on caregivers for dressing, grooming, bathing, feeding, bladder/bowel
- May forget to chew food or swallow
- May lose ability to sit up, hold head up and smile

Does everyone with Dementia exhibit challenging and irritating behaviors?

Those with Dementia suffer much confusion and fear, along with the loss of memory and ability to function independently. Damage to the brain resulting in challenging and irritating behaviors is inevitable. Each person will be unique in their behaviors. Some people will have more challenging behaviors than others. Families can better deal with challenging behaviors by learning caregiving tips and strategies.

Does everyone with Dementia turn mean and aggressive?

No, they do not. There seems to be a myth in our society that all people with Dementia turn angry and violent. This is definitely not true and is more the exception than the rule. On rare occasions a person with dementia may get extremely worked up and angry. Not always, but more often than not, when a person with dementia is upset their fire has been fueled by an untrained and uneducated caregiver, or by another person with dementia (if in a care facility). Families can better deal with angry and aggressive behaviors by learning caregiving tips and strategies from education classes, support groups or by reading books and internet sites. If behavior modification strategies don't work, collaborating with a physician and using anti-anxiety medications is sometimes an option.

Can Dementia be prevented or stopped from getting worse if one has already been diagnosed?

There are no proven preventions or ways to halt the course of the disease at this time. Research is showing that a healthy lifestyle that includes a nutritious diet, physical exercise, and brain challenging activities might help prevent the disease.

If someone has Dementia, will their children get it?

Not necessarily...but who knows. It is believed that a family history of Alzheimer's places one at higher risk. However, there are just as many people who get Alzheimer's with no prior family history of the disease. Scientists believe that genetics likely play a role in the disease, but they do not have all the answers or know all of the genes that are involved. It is possible that genes are involved and are perhaps triggered by something else that brings on the onset of the disease. Triggers could be things such as toxins in the environment or other health conditions such as diabetes, obesity, high blood pressure, heart disease, high cholesterol and head injury.



Caregiving Support

Who is the best person to be the caregiver of a person diagnosed with dementia?

A person with dementia will need a trusted caregiver or “co-pilot” to help them navigate the complicated course of their disease. This co-pilot can be a spouse or life partner, an adult child, an adult grandchild, any relative, or a close friend. This person should be willing and able to accept the stress and many challenges that occur when taking care of a person with dementia.

What kinds of skills will a caregiver need?

Caregivers must wear many hats and be skillful in numerous areas. Being responsible for the health and safety of another adult is no easy feat. Caregivers may be called upon to do things that they have never been responsible for before such as paying bills, tracking medications, providing personal care such as bathing, toileting, teeth brushing, shopping for clothes or groceries, planning and preparing meals, planning activities, styling hair, shaving, yard work, driving, navigating the health care system, and speaking on behalf of another person with regards to symptoms and needs.

What type of help might a caregiver need?

Caring for a person with dementia is very stressful and difficult to do without help. Caregivers might need:

- help finding resources
- education on the specific cause of dementia
- caregiving tips and strategies for understanding and caring for persons with dementia
- emotional support
- guidance with legal and financial issues
- help taking a break from caregiving to rejuvenate
- end of life support

Where can a family go for dementia support?

Hilltop offers a full spectrum of services and guidance and support for families dealing with dementia. Hilltop's Senior Life Options include dementia counseling and advice, dementia education classes for families in the community and professional staff, dementia caregiver support group, adult day program, and various levels of dementia assisted living.

Dementia Training, Resources and Advice

Tabby Wiest, 970-773-2263 | Dementia Education Classes and Support Group, 970-241-7798

Hilltop Dementia Specialists, are happy to sit down and talk with anyone needing dementia advice and guidance. Tabby is the Program Manager of Senior Daybreak of Hilltop, an adult day program for seniors with dementia. Our Dementia Specialists can help families create an individualized action plan for their situation, and provide a resource list of care and support options. This service is free and by appointment.



Senior Daybreak of Hilltop

Senior Daybreak is a day program for seniors who are memory impaired or frail who come to socialize and enjoy a variety of activities that are entertaining, stimulating, and physically active. While participants are at the program, their caregivers can take a break to rest and rejuvenate, knowing their loved one is well cared for in a safe, secure, and supportive environment. Most participants who attend live at home with their family and Senior Daybreak can help delay, or even prevent, placement of a loved one in a care facility.

Hope Harbor at The Commons

Hope Harbor is a neighborhood in The Commons for residents with mild confusion or early dementia who need a higher level of care and oversight. A person would be appropriate for Hope Harbor if they need reminders or assistance with meals, activities of daily living, and encouragement to attend social activities.

Companion Care at The Fountains

The Companion Care neighborhood at The Fountains is similar to Hope Harbor and is also designed for residents with early dementia who need a higher level of care and oversight. Due to the size and layout of the wing, Companion Care staff are able to provide ongoing line of sight supervision.

Safe Haven at The Commons

Safe Haven is a secure “locked” neighborhood in The Commons for individuals who have more advanced memory loss and confusion, and who may also have demonstrated the motivation and ability to “wander” outside of the facility resulting in the risk of getting lost and hurt. Safe Haven residents have access to a large secure outdoor patio and garden area.

Dementia Education & Support

Hilltop supports families whose loved one has memory loss and confusion in several ways:

- Navigating Memory Loss and Dementia Guide
- Caregiver Support Group
- Dementia Training Workshop
- Dementia Training Manual
- Aging Life Care Specialist for Guidance and Referral to Resources

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www.thefountainsgj.org

Dementia and Alzheimer's Care and Support

- Safe & secure adult day program for seniors
- Providing caregivers the flexibility & support they need to care for their loved ones at home
- Valuable information & support groups



970.241.7798
www.seniordaybreak.org

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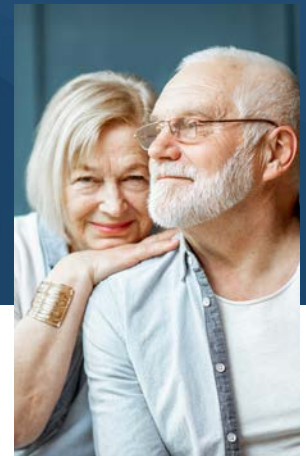
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