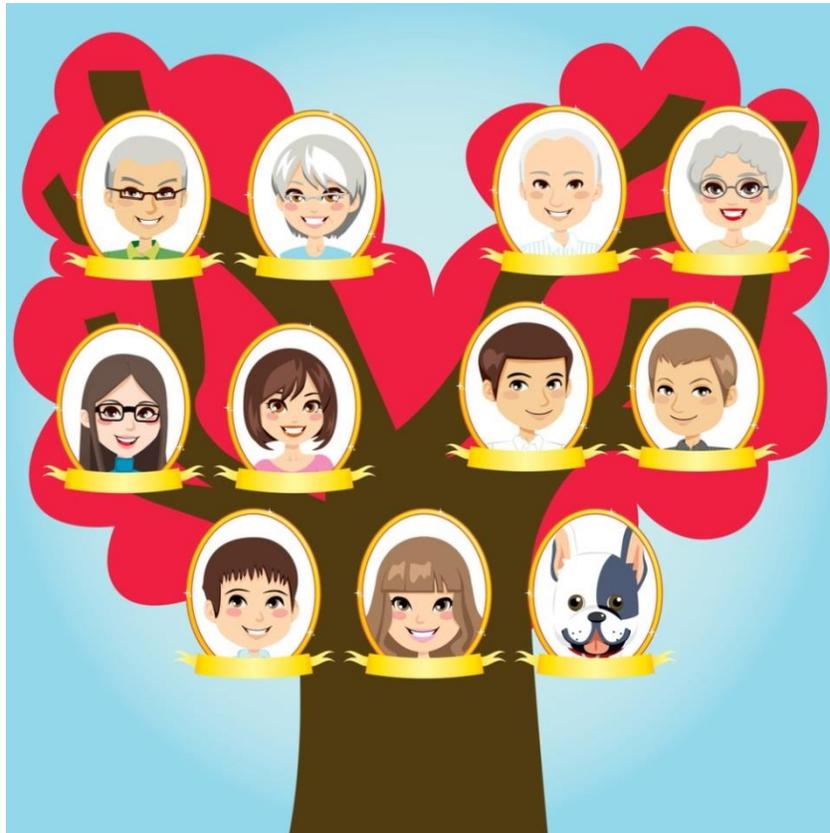


# *Dementia Caregiver Resource Guide*



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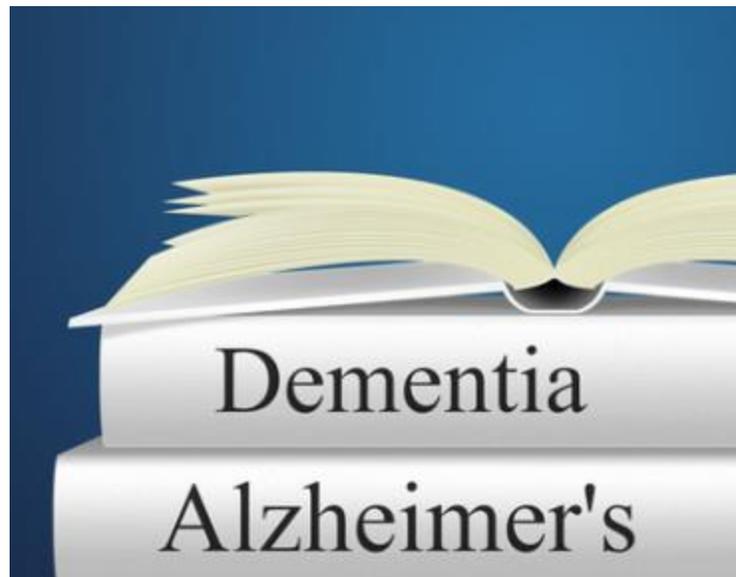
# Table of Contents

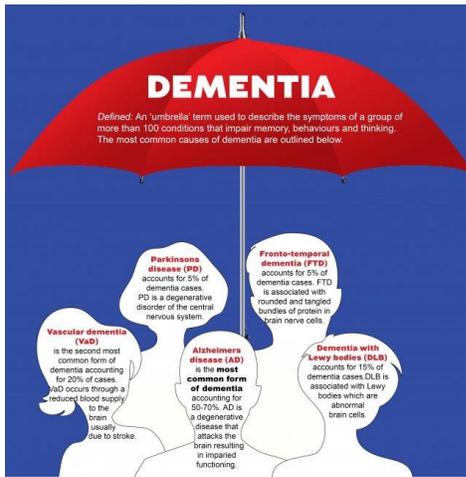
|  |    |
|--|----|
| Chapter 1: Introduction to Dementia .....                                  | 1  |
| What is dementia? .....  | 2  |
| Why get a diagnosis?.....  | 3  |
| How can I find out if I have dementia? .....                               | 4  |
| The healthy brain.....   | 5  |
| What happens to the brain in Alzheimer’s disease? .....                    | 5  |
| The brain –normal functioning and impaired functioning with dementia ..... | 9  |
| Chapter 2: Communication.....  | 11 |
| The basics of good communication .....                                     | 12 |
| Ensuring a positive connection.....  | 13 |
| Creative communication techniques.....                                     | 14 |
| How to complete a care task.....   | 15 |
| Communication thru the stages of Alzheimer’s disease.....                  | 16 |
| 10 Tips for effective communication with a person with dementia .....      | 19 |
| Chapter 3: Understanding Behaviors Related to Dementia .....               | 20 |
| Understanding behaviors (the way people behave or act) .....               | 21 |
| What can behaviors be linked to: .....                                     | 22 |
| How to manage personality and behavior problems: .....                     | 23 |
| 5 common behaviors that occur with dementia and what to do.....            | 24 |
| Responding to a challenging behavior.....                                  | 26 |
| Catastrophic reaction .....  | 27 |
| How can a catastrophic reaction be prevented?.....                         | 28 |
| Wandering .....  | 29 |
| Basic human needs and the language of behavior .....                       | 31 |
| Chapter 4: Safety .....  | 32 |
| General safety concerns for people with dementia:.....                     | 33 |
| Safety in the physical environment .....                                   | 34 |
| Home safety helpful hints.....   | 41 |
| Is it safe to leave the person with dementia home alone?.....              | 42 |

|  |    |
|--|----|
| Chapter 5: Activities .....  | 43 |
| Benefits of activities .....   | 44 |
| List of tips that help make an activity successful for the individual with dementia: ..... | 45 |
| Planning the day .....   | 46 |
| Writing the plan .....   | 47 |
| <b>50</b> Activities to do with an individual who has Alzheimer’s disease .....            | 48 |
| Chapter 6: Care Options .....  | 49 |
| Care options .....   | 50 |
| Choosing a care facility: .....  | 51 |
| Care facility checklist .....  | 52 |
| Emergency planning for the <i>What Ifs</i> .....   | 54 |
| Chapter 7: Caregiving .....  | 55 |
| Caregiver qualities .....  | 56 |
| The traits to be a good dementia caregiver .....   | 58 |
| Things the family can do to help healthcare providers .....                                | 59 |
| Introduction to my life tool .....   | 60 |
| Positive Approaches to caregiving .....  | 64 |
| Grief cycle in dementia caregiving .....   | 65 |
| Ways to stop guilt from dementia care .....  | 66 |
| Normal feelings and concerns caregivers have that lead to feelings of guilt .....          | 67 |
| Ten real-life strategies for dementia caregiving .....                                     | 68 |
| 10 Signs of Caregiver Stress .....   | 71 |
| Tips for coping/managing stress as a caregiver .....                                       | 72 |
| Chapter 8: Legal and Financial Concerns .....  | 73 |
| Plan ahead: legal and money concerns .....   | 74 |
| Overview of medical, legal, and financial planning documents .....                         | 76 |
| Appendix .....   | 77 |
| Books to help caregivers understand Alzheimer’s and related dementias .....                | 77 |
| Books to help children understand Alzheimer’s and related dementias .....                  | 78 |
| Dementia Internet Resources .....  | 79 |



# Chapter 1: Introduction to Dementia





## What is Dementia?

Dementia isn't a specific disease. Dementia is a medical condition that interferes with the way the brain works. Dementia describes a group of symptoms affecting memory, thinking and social abilities severely enough to interfere with daily functioning.

### Symptoms:

1. Memory Loss
2. Changes in how people talk
3. Changes in how people act
4. Trouble completing day to day activities
5. Difficulty learning new skills

### Types of Dementia:

- **Alzheimer's disease** is the most common, progresses slowly; and gradually destroys memory, reason, judgment, language, and eventually the ability to carry out even simple tasks
- **Vascular dementia** happens when part of the brain doesn't get enough blood carrying the oxygen and nutrients it needs
- **Acquired brain injury** happens when there is some type of injury or lack of oxygen to the brain
- **Fronto-temporal Dementia** affects planning and judgment; emotions, speaking and understanding speech; and certain types of movement
- **Dementia with Lewy Body** leads to a decline in thinking, reasoning and motor skills

Treatment: At this time there is no cure for dementia, however there are treatments to help manage symptoms

## Why get a Diagnosis?

Memory concerns are not always caused by a dementia. Your doctor will determine what tests you need to identify the reason of your memory issues. Whether you have a diagnosis is dementia or another medical condition, this will determine the treatment plan that is best for you.

| <b>Treatable conditions that may be causing your memory loss</b> |
|--|
| <b>Medication side effects</b>                                   |
| <b>Thyroid, kidney or liver disorders</b>                        |
| <b>Vitamin B12 deficiency</b>                                    |
| <b>Brain tumor</b>   |
| <b>Depression</b>  |
| <b>Lyme disease</b>  |
| <b>Delirium</b>  |

### **What are the advantages to an early diagnosis?**

- Less anxiety and stress regarding the unknown
- A better chance of benefitting from treatment
- More time to plan for the future

If the diagnosis is a dementia, there are medical trials being held to reduce the cognitive deficits (memory, language, thinking, etc.), and an early diagnosis is needed to be part of research trials

### How can I find out if I have dementia?

The first step is to make an appointment with your primary care provider for a physical exam and discuss your concerns and symptoms. Be sure to have your support person with you. They can also help to make sure your questions and concerns are being addressed.

### During the doctor's visit, you should talk about:

|                 |   |
|-----------------|---|
| Health concerns | Discuss what brought you to the doctor and your fears                                     |
| Medications     | Bring a list of all your medications from the doctor and all over-the-counter medications |

### What to expect at your doctor appointment:

|   |
|---|
| Physical exam   |
| Blood and urine tests   |
| Neurological exam   |
| Cognitive exam  |
| Referral to specialist (neurologist, neuropsychologist, geriatrician, geriatric psychiatrist) |



## The healthy brain

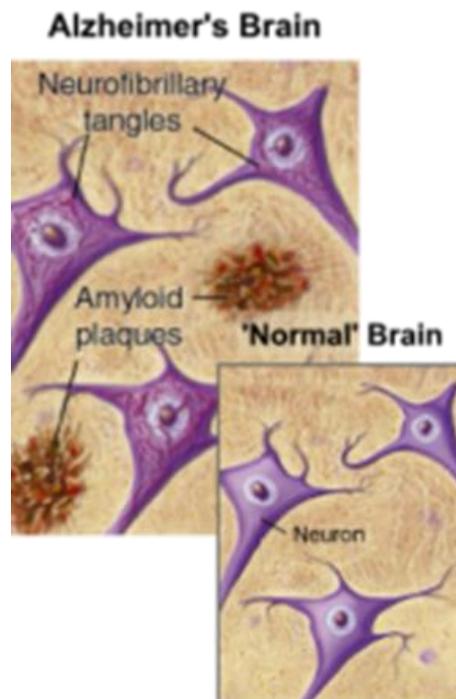
Takes in information  
Stores information  
Processes information  
Retrieves information

When a person has Alzheimer's disease, the brain changes and these tasks become more difficult.

## What happens to the brain in Alzheimer's disease?

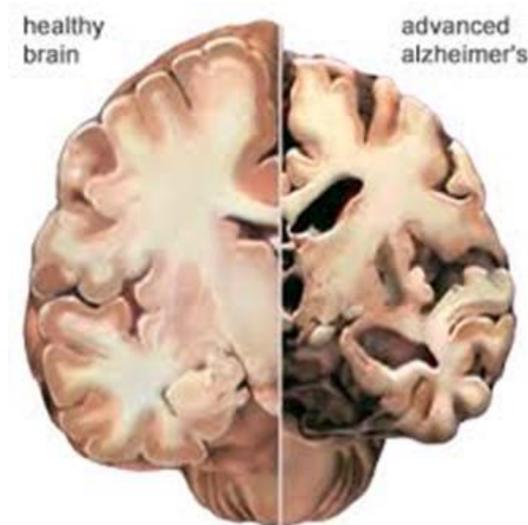
People with Alzheimer's disease have a lot of abnormal structures called plaques and tangles in the brain

- Plaque is a deposit of a type of protein fragment that builds up in the spaces between nerve cells
- Tangles are twisted fibers of another type of protein that build up inside nerve cells



The buildup of these two proteins causes a loss of connections between brain cells. This damage and loss of nerve cells causes memory failure, personality changes, language problems and other symptoms of Alzheimer's disease

The brain tissue shrinks throughout the disease process which causes the memory decline.



At this time, scientists know that Alzheimer's disease involves a failure of nerve cells, but they still don't know why this happens. Scientists have been able to identify certain risk factors that increase the likelihood of developing Alzheimer's.

Risk Factors Include:

- Age
- Family history
- Genetics

| Symptoms and Stages of Alzheimer's Disease |   |   |  |
|--|---|---|--|
| Ability Affected                           | Early Stage Alzheimer's   | Middle Stage Alzheimer's  | Late Stage Alzheimer's   |
| <b>Memory</b>                              | Has trouble with remembering recent events; may have difficulty remembering names, finding the right word, and remembering thoughts; misplaces familiar items, may forget appointments, or get lost during a trip to familiar place | Is largely unaware of all recent events and experiences; can still remember distant past; Cannot form new memories; Forgetfulness of events or about one's own personal history; Unable to remember their own address or telephone number | Has no recent or past memory   |
| <b>Cognitive Ability</b>                   | Has difficulty handling finances; Having greater difficulty performing tasks in social or work settings; may have difficulty telling time; may no longer be capable of working; Increasing trouble with planning or organizing      | Has great difficulty making decisions and choices; has difficulty concentrating and easily loses flow of conversation; needs 1 step instruction to complete tasks ;shows poor judgment; loses sense of time and place                     | Has little noticeable cognitive function   |
| <b>Motor Skills</b>                        | Still has generally good coordination and motor skills; may have slowed reaction time   | Loses coordination and balance; may be unsteady; ; bump into things and fall easily; may have difficulty walking; loses ability to write legibly; Trouble controlling bladder and bowels sometimes  | Usually loses ability to walk and sit up; may lose ability to swallow  |
| <b>Mood and Behavior</b>                   | May Experience mood swings; socially withdrawn; easily distracted; seeks out and prefers familiar; less spontaneous; less initiative; may deny forgetfulness and confusion  | Experiences frequent mood swings; is increasingly self-absorbed; insensitive to feelings of others; may suffer sleep problems; Personality and behavioral changes, including suspiciousness and delusions or compulsive actions           | Is often agitated; may not recognize primary caregiver; Lose awareness of recent experiences as well as of their surrounding |

| <b>Ability Affected</b>                  | <b>Early Stage Alzheimer's</b>  | <b>Middle Stage Alzheimer's</b>  | <b>Late stage Alzheimer's</b>  |
|--|---|--|--|
| <b>Ability to complete personal care</b> | Carries out personal care with little or no assistance  | Needs assistance with personal care, for help choosing proper clothing for the season or the occasion and putting on clothing properly; may have fear of bathing ; may have difficulty with toileting  | Needs extensive assistance with personal care; bathing, grooming, dressing, and feeding  |
| <b>Language</b>                          | May communicate less, but speech is generally unaffected; has slightly reduced vocabulary; has problems coming up with the right word or name; is occasionally vague; may say irrelevant things | Talk less or may repeat words or phrases continuously; has slower speech filled with pauses and interruptions; uses complete sentences infrequently; may make little sense; has significantly reduced vocabulary; may lose ability to understand written and/or spoken language; may invent words; must have instructions repeated | May lose ability to speak altogether or vocabulary may be limit to one or two words; may be able to repeat words or phrases without understanding meaning; may repeat words continuously; may be unable to understand what is being said |

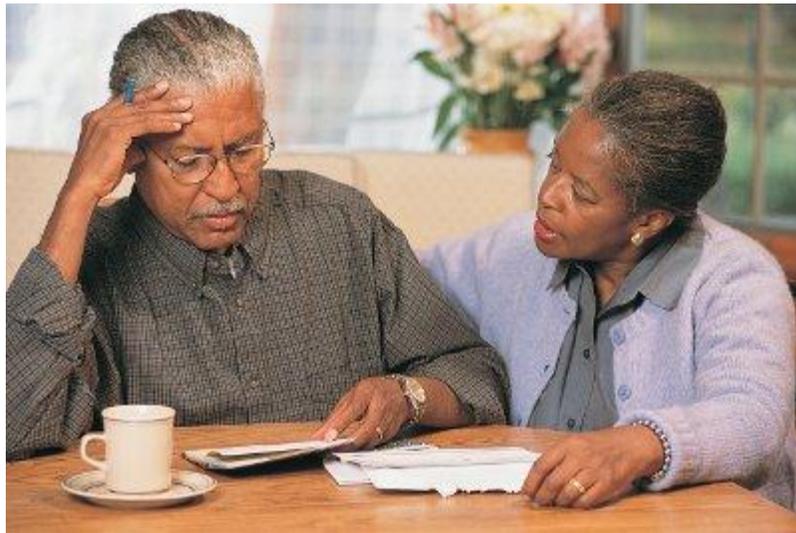
## The brain –normal functioning and impaired functioning with dementia

Each part of the brain has a function and depending on where in the brain Alzheimer’s disease is present different challenges will occur. The person with dementia will have impaired functioning and the caregiver must learn new ways of responding to help the person be successful day to day. Below is a table showing the normal and impaired functioning of the brain and interventions to use based on the part of the brain that is affected.

| Part of the Brain   | Normal Functioning   | Impaired Functioning   | Interventions  |
|---------------------|--|--|--|
| <b>Hippocampus</b>  | <ul style="list-style-type: none"> <li>-Involved in storing recent memories</li> <li>-Sensory information is received and placed into storage for later retrieval</li> </ul>   | <ul style="list-style-type: none"> <li>-unable to store new information</li> <li>-Gets lost easily</li> <li>-repeats questions</li> <li>-is confused</li> <li>-no sense of time</li> <li>-loses possessions</li> </ul> | <ul style="list-style-type: none"> <li>-provide eye contact and cheerful body language</li> <li>-validate feelings</li> <li>-answer questions as if they were heard for the first time</li> <li>-redirect to non-confusing activities</li> </ul> |
| <b>Frontal Lobe</b> | <ul style="list-style-type: none"> <li>-Involved in planning, decision making and purposeful behavior</li> <li>-Personality, judgment, attention span</li> <li>-Regulates mood</li> <li>-Controls impulses and social appropriateness</li> </ul> | <ul style="list-style-type: none"> <li>-cannot plan, initiate or carry out complex activities</li> <li>-problems with new situations</li> <li>-easily distracted</li> <li>-Personality changes common</li> </ul>       | <ul style="list-style-type: none"> <li>-give step by step directions one at a time</li> <li>-Give prompts, visual cues to start an activity</li> <li>-Keep environment safe</li> <li>-Reduce environmental stimuli and noise levels</li> </ul>   |

| <b>Part of the Brain</b> | <b>Normal Functioning</b>   | <b>Impaired Functioning</b>   | <b>Interventions</b>  |
|--------------------------|---|---|---|
| <b>Occipital Lobe</b>    | <ul style="list-style-type: none"> <li>-Receives and processes visual information from the eyes</li> <li>-Analyzes visual information for orientation, position and movement</li> </ul>                 | <ul style="list-style-type: none"> <li>-unable to process rapid body movements</li> <li>-loses sense for 3 dimensional space</li> <li>-loses peripheral vision</li> </ul>   | <ul style="list-style-type: none"> <li>-Always approach from the front</li> <li>-maintain eye contact</li> <li>-avoid patterned floor and wall designs</li> <li>-assist with slow and deliberate movements</li> </ul> |
| <b>Temporal Lobe</b>     | <ul style="list-style-type: none"> <li>-Responsible for perception</li> <li>-Processes language and ability to speak and understand language</li> <li>-Puts together the parts to make sense</li> </ul> | <ul style="list-style-type: none"> <li>-Develops aphasia-a speech impairment resulting in an inability to make oneself understood or to understand others</li> <li>-examples-word loss, disorganized sentences, make up answers to cover up word deficit</li> </ul> | <ul style="list-style-type: none"> <li>-early on- fill in missing words</li> <li>-later on- prompt with gestures body language, hand on hand or physical prompts</li> <li>-use positive body language</li> </ul>      |
| <b>Parietal Lobe</b>     | <ul style="list-style-type: none"> <li>-Sensory perceptual part of the brain</li> <li>-Processes sensations such as pain, touch, heat</li> <li>-words put together into thoughts</li> </ul>             | <ul style="list-style-type: none"> <li>-develops agnosia-cannot make sense of the senses, misidentifies familiar objects, and does not understand their purpose</li> <li>-cannot follow auditory and visual cues</li> </ul>   | <ul style="list-style-type: none"> <li>-Assist with prompts, gestures, demonstration and body language</li> <li>-give prompts that help clarify the purpose or goal of an object</li> </ul>                           |

## Chapter 2: Communication



## The basics of good communication

- Approach the person from the front
- Always make eye contact
- Identify yourself
- Call individual by name



## Be aware of your communication style

- Use calm tone of voice
- Don't speak too loud or too soft
- Body language, including hand gestures, makes up 80% of how you communicate
- Avoid long explanations
- Speak slowly using simple words
- Avoid interrupting and arguing with them
- Avoid confrontation and remain calm
- Make positive suggestions instead of negative
  - Positive "Let's go this way"
  - Negative "Don't go that way"

## Listen carefully

- Try to understand the person's feelings and emotions
- It's okay to acknowledge bad feelings as well as good ones
- Give plenty of encouragement and reassurance

## Ensuring a positive connection

- ✓ Provide a calm and quiet environment
- ✓ Keep things simple
- ✓ Limit choices to no more than 2 things
- ✓ Avoid open ended questions
- ✓ Read body language for pain, hunger, thirst, or need to use the bathroom
- ✓ Avoid arguing
- ✓ Allow the person their own reality-agree with them, validate their feelings, and try to reminisce or redirect them to another activity
- ✓ Sing or play soft music as this can bring a sense of calm
- ✓ Engage the person with an activity as this may replace anxious feelings with feelings of enjoyment



## Creative communication techniques

**Visual Cues** can jump start the brain to remember what to do. They prompt the person to perform basic tasks

### Examples of visual cues are:

- Signage which can be written words or pictures. The written word can help remind what to do, such as “take medications” or “turn off the faucet”; Pictures can label the contents of a dresser drawer or kitchen cabinet.
- Extra lighting or contrasting colors can highlight an area such as the toilet or a stairway.
- Memory aids such as a calendar, a schedule of daily routine, a large button phone with pictures of important people, or timers can help.
- Mirroring a task
  - For example: eating across from each other, helps start the task of eating

**As the disease progresses, visual cues will need to be changed**



## How to complete a care task

Get the person's attention by calling their name and making eye contact. If the person is lost in thought, direct his attention to you by gently touching his arm or his leg.

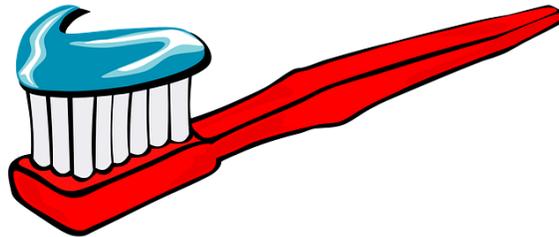
Tell the person what you want them to do. Use short sentences and simple phrases.

*"It's time for your shower"*

*"That shirt is dirty. Let's get you a different shirt"*

Encourage the person to participate in their own care as much as possible. Offer short, clear one step instructions and give the person enough time to process what you are saying. Allow them time to complete the requested action before giving the next instruction.

Offer praise and reassurance as needed



## What to do if the person says NO to care

Offer redirection. Change the subject or give the person something else to focus on such as old photos, playing favorite music or putting in a favorite DVD or movie

Wait until the person is calm again, and then re-approach them with a positive attitude as if the previous conflict never happened

- For example: Don't say, "Are you ready for dinner now?", instead say, "Hi Dad, It's time for dinner."
- If the person continues to say no to care, ask yourself how important the issue really is. If it's not that important – let it go for another day

## Communication thru the stages of Alzheimer's disease

### What to expect in the early stage

They can make decisions about future care

They can convey thoughts and feelings through language

They may have difficulty finding the right words

They may take longer to speak or respond

They may withdraw from conversations

### How to connect in the early stage

Ask the person directly how to help with communication (i.e.: fill in words)

Keep sentences clear and straight forward

Allow plenty of time for conversation

Include the person in conversations that affect them (don't whisper behind their back)

Recognize the effects of your mood and actions on the person



## What to expect in the middle stage

They can still use basic words and sentences  
They rely more on tone of voice, facial expressions, and body language  
They continue to need emotional connections and meaningful activities  
They have increased difficulty finding the right words  
They may use familiar words repeatedly  
They may invent new words to describe familiar things  
They easily lose their train of thought  
They may speak less frequently

## How to connect in the middle stage

Approach the person from the front, say who you are, and call the person by name  
Maintain eye contact  
If seated, get at their eye level  
Avoid correcting and arguing  
Pay attention to your tone of voice  
Take your time  
Respond to the person's feeling behind their statement  
Use short sentences and basic words  
Limit distractions  
Be patient  
Provide visual cues and gestures (signs, pictures, smiles)  
Avoid quizzing  
Focus on the feelings not the facts; validate feelings and redirect the person if necessary



For example the person says: *“I want to go home”*, you say, *“Tell me about your home”*

Or the person says: *“I can't find my purse”*, you say *“You look upset, let me help you look for the purse.”*

**Be aware that your mood and actions affects the person with memory loss**

## What to expect in the late stage

Communication is reduced to a few words or sounds

May be able to respond to familiar words or phrases that they understand

## How to connect in the late stage

Use all 5 senses to communicate; touch, sight, sound, smell, taste

Understand and accept what you can and cannot change

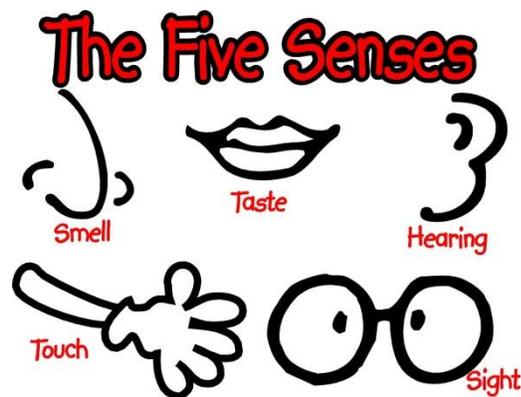
Help meet the needs while soothing and calming the person

Use a gentle affectionate voice when talking

Make the person feel safe and happy

Keep talking even when they can't

Be aware that your mood and actions affect the person with memory loss



## 10 Tips for effective communication with a person with dementia

**Never Argue-----Agree**

**Never Reason-----Divert**

**Never Shame-----Distract**

**Never Lecture-----Reassure**

**Never Remember-----Reminisce**

**Never Say “I told you”-----Repeat**

**Never say “You can’t”-----Say “Do what you can”**

**Never Command or Demand-----Ask or Model**

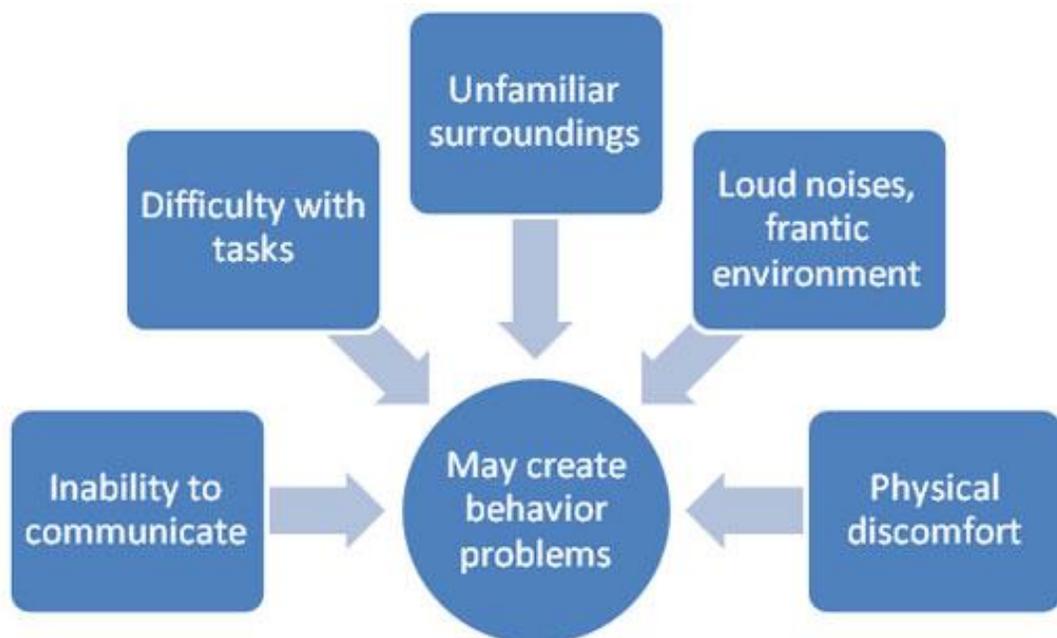
**Never Condescend-----Encourage or Praise**

**Never Force-----Reinforce**



**“I told you so”**

## Chapter 3: Understanding Behaviors Related to Dementia



## Understanding behaviors (the way people behave or act)



Alzheimer's disease and related dementias can cause a person to act in different ways. These behaviors can be different for each person throughout the stages of the disease.

### **Common changes in the person's personality and behavior may include:**

- ❖ Getting upset, worried and angry more easily
- ❖ Acting depressed or not interested in things
- ❖ Hiding things or believing other people are hiding things
- ❖ Wandering away from the home
- ❖ Pacing
- ❖ Hitting, kicking, or biting
- ❖ Misunderstanding or confusion of what they see or what they hear
- ❖ May become more focused on sex
- ❖ May stop bathing
- ❖ May want to wear the same clothes every day

### **Some reasons why these behaviors may happen:**

- ❖ There are changes taking place in the brain
- ❖ They are not understanding what is happening around them
- ❖ The task is too hard
- ❖ They are in pain
- ❖ They have trouble communicating

## What can behaviors be linked to:

### The environment:

1. The environment is too big or cluttered. This can be confusing to the person.
2. There is too much noise, which increases the stress for the person.
3. There is a lack of structure in their daily routine.

### Completing a task:

1. The task maybe too hard; you can use cueing and assistance to help the person complete the task.
2. The task may have too many steps. Try breaking down the task into 1 step at a time.

### Physical health:

1. The effects of a medication on the person.
2. It could be they have impaired vision or hearing.
3. It could be related to an acute illness (UTI, GI bug, fever).
4. The effects of another chronic illness (CHF, diabetes, angina, COPD).
5. It could be related to dehydration.
6. It could be related to constipation.
7. The effects of fatigue.
8. They may have physical discomfort such as hunger, feeling too hot or too cold.



## How to manage personality and behavior problems:

1. Rule out medical causes (especially if there is a quick change in behavior).
2. Pay attention to what the person is saying both verbally and non-verbally.
3. Validate their feelings and try to distract them.
4. Refocus their attention whenever possible.
5. Promote a sense of feeling safe and secure and offer reassurance often.
6. If the person with dementia is upset, sometimes saying you're sorry may help.
7. Understand their behavior is how they communicate.
  - For example: if they hit you, you may have startled them or you may be too physically close to them.
  - Try not to take it personally, they are acting on instinct and are trying to feel in control.



## 5 common behaviors that occur with dementia and what to do

| Behavior          | Definition   | Causes   | What to do   |
|-------------------|--|--|--|
| <b>Suspicion</b>  | Occurs when the person with dementia sees things in new or unusual ways. This may be due to a misunderstanding of what they see or hear and is caused by the brain disease | <p>Not including person with dementia in conversation or talking about person with dementia like they are not there</p> <p>Poor vision or hearing</p> <p>Too much stimulation causing a misunderstanding of what is happening around them</p>  | <p>Don't argue, reason or explain</p> <p>Offer a simple answer sharing your thoughts</p> <p>Switch the focus to another activity or ask them to help with something</p> <p>Duplicate any lost items if the person is often searching for a specific item</p> <p>Listen to what is upsetting the person and accept their reality, validate this feeling, be reassuring and let them know you care</p> |
| <b>Aggression</b> | At times a person with dementia is unable to recognize or know how to communicate their needs  | <p>Poor impulse control due to the disease process</p> <p>Frustration when trying to do something they cannot do anymore</p> <p>Overstimulation</p> <p>Discomfort (pain, thirst, hunger)</p> <p>Response to a caregiver's stress</p> <p>Feeling scared and someone being in their personal space</p> | <p>Know what the person likes, dislikes, and their social history</p> <p>Use calming tactics such as an apology, a smile, offer a snack or to walk with them</p> <p>If nothing works, leave them alone until they have calmed down</p>   |

| <b>Behavior</b>                    | <b>Definition</b>  | <b>Causes</b>  | <b>What to do</b>  |
|------------------------------------|--|--|--|
| <b>Confusion</b>                   | <p>Person with dementia may not recognize familiar people, places or things and may forget the purpose of common items</p> <p>“Sundowning” is a group of symptoms that may occur at the end of the day and into the night and causes increased confusion</p> | <p>A change in living arrangements</p> <p>A different daily routine</p> <p>Medical reasons such as an infection (UTI) or low blood sugar</p> <p>Delirium</p> <p>Feeling tired</p> <p>Getting day and night mixed up</p> <p>Difficulty separating reality from dreams</p> | <p>Stay calm, do not take it personally</p> <p>Respond with simple details</p> <p>Show photos or other reminders</p> <p>Offer corrections as suggestions (“I think he is your brother Sam”)</p> <p>Try to keep the same routine day to day</p>   |
| <b>Feeling Anxious or Agitated</b> | <p>Person with dementia often feels very anxious and becomes tense or restless. It becomes hard to let go of their fears and needs and to rely on a caregiver for their care and direction.</p>  | <p>Changes in environment</p> <p>Travel</p> <p>Hospitalization</p> <p>Moving to a new place</p> <p>Changes in the caregiver</p> <p>Fear and fatigue from trying to make sense out of a confusing world</p>   | <p>Try to understand what is causing the feeling</p> <p>Create a calm environment</p> <p>Provide reassurance</p> <p>Begin a new activity that might help the person relax such as music, art, taking a walk</p> <p>Monitor their comfort; could their feelings be related to hunger, thirst, or pain</p> |
| <b>Repetition</b>                  | <p>When the person with dementia does or says something over and over again. They may be looking for comfort, security, or something familiar</p>  | <p>Memory Loss</p> <p>Not knowing what is happening or a separation from loved one</p> <p>Not able to express an emotion such as fear, insecurity, and anger</p>   | <p>Focus on the person’s feeling and not the behavior, offer reassurance and try to distract the person with a favorite activity</p> <p>Be calm when answering repeated questions; be patient</p>  |

## Responding to a challenging behavior

Dealing with challenging behaviors is a process. Try to think of it as a puzzle instead of a problem. This will help reduce the negativity of the situation. There are no quick solutions to manage challenging behaviors. Patience and creativity are helpful traits when caring for a person with dementia.

### Things to consider:

- We can accept the behavior and provide ways to help the person by offering reassurance or redirection
- We can change our approach thru learning new responses
- We can adjust our expectations
- We can remind ourselves the person with dementia is doing the best they can
- Look at the person's behavior as communication; I want...I need...I feel
- Avoid using labels as the label may hide the real problem ( i.e. aggressive, stubborn, wandering, socially inappropriate)
- We can use medications if needed for safety or to minimize extreme behaviors

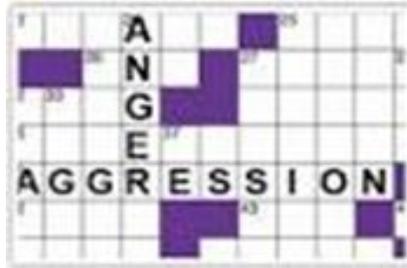
### Solutions to behavior problems:

- Observe the behavior objectively; do not REACT.
- Empathize "I guess I might feel the same way you do."
- Listen
- Label the emotion. ("You look upset. Can I help?")
- Reframe by asking yourself if the behavior is against you or a response to a situation

### What could the mis-behavior mean?

- A feeling of I need attention could result in an angry outburst or the person being passive.
- A feeling of I don't want to fail could result in the person refusing to participate.
- A feeling of I want to be in control could result in behavior that is disruptive, yelling, and criticizing.
- A feeling of I want to get back at you could result in the person being rude or retaliation.

## Catastrophic Reaction



**Some people with dementia experience what is called a catastrophic reaction. This type of reaction or behavior occurs in a person with dementia when the situation overwhelms their ability to think or respond appropriately. It is a sudden or drastic outburst or change in the person’s mood or behavior.**

**Examples of Catastrophic Reactions are:**

- Physical reaction such as hitting, kicking or pulling hair
- Emotional reaction such as shouting, screaming or crying uncontrollably
- Increased tension and stubbornness

**Why do Catastrophic Reactions occur in dementia?**

- The person feels lost or afraid
- There are too many people around or being in a new place
- The person is being asked too many questions, especially the question “Why?”
- The person is being yelled at by the caregiver
- The person senses that the caregiver is upset

**The most common cause for a person with dementia to have a catastrophic reaction is when they are being helped with personal care tasks.**

**The most common time of day for a catastrophic reaction to occur is dinner time.**



### **How can a Catastrophic Reaction be prevented?**

- Approach the person from the front, rather the back or side to prevent startling them.
- As the caregiver try to appear calm and relaxed.
- Know what the person likes and doesn't like.
- Explain clearly what you would like to have the person do before attempting to do it. For example say: "Dinner's ready, let's walk to the table together."
- Give directions one step at a time.
- Don't criticize or argue.
- Keep the daily routines structured and the same day to day.

### **How should a caregiver respond to a Catastrophic Reaction?**

- Give the person physical space
- Don't use restraint or force
- Be respectful, and don't talk down
- Use the person's name
- Allow the person extra time to calm down
- Reassure the person
- Redirect the person's attention to focus on something else
- If a catastrophic reaction is unusual for this person, consider the possibility that the person may have a health issue and discuss it with the person's doctor.

## Wandering

**A person with dementia may not remember where they live. The research has shown that 6 out of 10 people with dementia will wander away from home and become lost. This can happen to the most careful caregivers and is a huge safety concern.**

### **Behavioral signs that a person may wander and strategies to stop wandering:**

- The person tries or wants to “go home” even when they are at home.

***What you can do:*** Try to redirect to another room for a snack or activity

- The person tries or wants to “go to work” or other former obligation

***What you can do:*** Use a fiblet (For example, reassure him that today is a day off from work)

- Person is restless or pacing

***What you can do:*** Offer exercise or other meaningful activity throughout the day

- Person appears nervous or anxious

***What you can do:*** Reduce noise level or other distractions to reduce this feeling



## **Possible things that may trigger wandering are:**

- A certain time of day or any clue before attempting to wander
- Anything new in the person's life (a recent move, new medication)
- The person may be having an hallucination
- If the person has a route that they usually take you can use this route for a daily walk

## **How to reduce the risk of wandering**

- Keep to a daily routine that includes meaningful activity, and enough physical exercise that will distract the person from wandering and provide an outlet for energy
- Place a slide bolt on the top or the bottom of the exit door
- Use child safe doorknob covers
- Attach a bell or electronic device that rings when the door opens
- Keep hats, coats, keys away from the exit door and out of sight
- Try putting a "stop" sign on the inside of exit doors
- Disguise exit doors at night with a curtain

**Enroll the person in the Medic Alert and Alzheimer's Association Safe Return program- call 1-800-272-3900 for information and to enroll.**



Live 24-hour emergency response for  
wandering and medical emergencies



**safe return**

alzheimer's  association

## Basic human needs and the language of behavior

People with Alzheimer’s disease exhibit certain behaviors when their basic human needs are not met. In the chart below, Professor Tom Kitwood, author of the book Dementia Reconsidered, describes the five basic human needs that are not met for someone with dementia, their typical behaviors and interventions to help meet these needs. As caregivers, our goal is to interpret the language of behavior and do our best to meet that need.

| Basic Need Not Met  | Typical Behaviors                                       | Things to do   |
|---|---|--|
| <b>Inclusion</b> - the need to be part of a larger group                              | Hovering, clinging, intrusiveness and shadowing         | Involve in a group activity program.<br>Invite her to stand with you while you are speaking to someone else.   |
| <b>Occupation</b> - the need to feel meaningful by exercising abilities and strengths | Boredom, wandering, resisting care, increased agitation | Empower her to do as much as possible.<br>Engage in familiar tasks like household chores, cooking, cutting coupons or sorting things   |
| <b>Attachment</b> - the need to bond with another person                              | Fear, paranoia, delusions, exit seeking                 | Consistent care partners.<br>Befriend other residents in similar stages.<br>Encourage and help with family visits.   |
| <b>Comfort</b> - the need to feel tenderness, closeness, warmth and security          | Anxiety, fear, panic, anger                             | Hugs, hand holding, scratching someone’s back, saying, “I love you”  |
| <b>Identity</b> - The need to have one’s uniqueness affirmed by others                | Depression, withdrawal, isolation, distrust             | Know the life story.<br>Good communication techniques make eye contact.<br>Use her name often.<br>Introduce her to others telling others something important about her (“Hi, this is Sadie, she has 10 children.”) |

## Chapter 4: Safety



## General safety concerns for people with dementia:

People with dementia become increasingly unable to take care of themselves. As a caregiver, you face the ongoing challenge of adapting to each change in the person's behavior and functioning.

### **Think Prevention**

- Checking the safety of your home will help you take control of some of the potential problems that may create hazardous situations.

### **Adapt the environment**

- It is more effective to change the environment than to change most behaviors. You can change the environment to decrease the hazards and stressors that accompany these behavioral and functional changes.

### **Minimize danger**

- A safe environment can be a less restrictive environment where the person with AD can experience increased security and more mobility.



## Safety in the physical environment

As the disease progresses the five senses change and the physical environment needs to be modified.

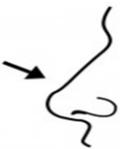
### Impairment of the Senses:

#### Vision:



- Create color contrast between floors and walls to help the person see depth
- Use dishes and placemats in contrasting colors for easier Mark the edges of steps with brightly colored strips of tape to outline changes in elevation
- Place brightly colored signs or simple pictures on doors to important rooms for easier identification
- Be aware that a small pet that blends in with the floor or lies in walkways may be a hazard

#### Smell:



- A loss of or decrease in the sense of smell is common in dementia
- Install smoke detectors and check them frequently. The person with dementia may not smell smoke or many not associate it with danger
- Keep refrigerators clear of spoiled foods

#### Touch:



- People with dementia may experience loss of sensation or may no longer be able to interpret feelings of heat, cold or discomfort
- Adjust water heaters to 120 degrees to avoid scalding water
- Color code separate water faucet handles, with red for hot and blue for cold
- Place a sign over the oven, coffee maker, toaster, crock-pot, iron and other potentially hot appliance that says **DO NOT TOUCH OR STOP! VERY HOT**
- Use a thermometer to tell you whether the water in the bathtub is too hot or too cold
- Remove furniture with sharp corners or pad them to reduce potential for injury

## Taste:



- Individuals with dementia may lose taste sensitivity. As their judgment declines, they also may place dangerous things in their mouth.
- Keep all condiments such as salt, sugar, or spices away from easy access.
- Remove or lock up medicine cabinet items such as toothpaste, perfume, lotions, shampoos, rubbing alcohol, or soap, which may look or smell like something edible.
- Consider a childproof latch on the refrigerator, if necessary.
- Keep the toll-free poison control number 1-800-222-2221 by the telephone.
- Keep pet litter boxes inaccessible to the individual with dementia.

## Hearing:



- Individuals with dementia may have normal hearing, but they may lose their ability to understand what they hear correctly.
- Avoid excess noise in the home such as having the stereo and the TV on at the same time.
- Be sensitive to the amount of noise going on outside, and close windows or doors, if necessary.
- Avoid large gatherings of people in the home if the person with dementia shows signs of being uncomfortable in crowds.
- Check hearing aid batteries.

## Home safety: room to room

### Front entrance:

- Remove all scatter rugs and throw rugs
- Use textured strips or nonskid wax on hard wood floors to prevent slipping

### Kitchen:

- Install childproof door latches on storage cabinets. Lock away **ALL** household cleaning products, matches, knives, scissors, blades, small appliances, and anything valuable
- If medication (prescription or over the counter) are kept in the kitchen, store them in a locked cabinet
- Remove all scatter rugs and floor pads from the floor
- Remove knobs from the stove, or install an automatic shut off switch.
- Keep a night light in the kitchen
- Remove or secure the “Junk Drawer”.
- Remove artificial fruits or vegetables or food shaped kitchen magnets, which might appear to be edible.
- Insert a drain trap in the kitchen sink to catch anything that be put down the drain
- Consider dismantling the garbage disposal.



## **Bedroom:**

- Assume the reasons a person with dementia might get out of bed, such as hunger, thirst or need to go to the bathroom.
- Use a night light
- Use an intercom device to alert you to any noises indicating a fall or need for help.
- Remove scatter rugs
- Remove portable heaters
- Be cautious when using electric mattress pads, electric blankets and heating pads, all of which can cause burns and fires
- If the individual with dementia is at risk of falling out of bed, place mats next to the bed, as long as they do not create a greater risk of accident
- Use transfer or mobility aids

## **Living Room:**

- Clear all walk area of electrical cords
- Remove scatter rugs or throw rugs
- Place decals at eye level on sliding glass doors, picture windows or furniture with large glass panels to identify the glass pane
- Do not leave the person with dementia alone with an open fire Consider alternative heating sources. Remove matches and cigarette lighters
- Keep the remote controls for the television, DVD player, and stereo system out of sight



## **Bathroom:**

- DO not leave a severely impaired person with dementia alone in the bathroom
- Remove the lock from the bathroom door to prevent the person with dementia from getting locked in
- Place nonskid adhesive strips, decals, or mats in the tub and shower.
- Use an extended toilet seat with handrails, or install grab bars beside the toilet
- Install grab bars in the tub/shower. A grab bar in contrasting color to the wall is easier to see
- Use a plastic shower stool or bench and a handheld showerhead to make bathing easier
- In the shower, tub, and sink, use a single faucet that mixed hot and cold water to avoid burns
- Adjust the water heater to 120 degrees to avoid scalding tap water
- Insert drain traps in sinks to catch small items that be lost or flushed down the drain
- Store medications in a locked cabinet
- Remove cleaning products from under the sink, or lock them away.
- Remove small electrical appliances from the bathroom Cover electrical outlets



## **Laundry Room:**

- Keep the door to the laundry room locked if possible
- Lock all laundry products in a cabinet
- Remove large knobs from the washer and dryer if the person with dementia meddles with machinery
- Close and latch the doors and lids to the washer and dryer to prevent objects from being placed in the machines

## **Garage/Shed/Basement**

- Lock access to all garages, sheds, and basements if possible
- Inside a garage or shed, keep all potentially dangerous items, such as tools, tackle, machines and sporting equipment, either locked away in cabinets or in appropriate boxes or cases
- Secure and lock all motor vehicles and keep them out of sight if possible
- Keep all toxic materials, such as paint, fertilizers, gasoline, or cleaning supplies, out of view
- If a person with dementia is permitted in a garage, shed basement, make sure the area is well lit and that stairs have a handrail and are safe to walk up and down



## Outside the Home

- Keep steps sturdy and textured to prevent falls in wet or icy weather
- Mark the edges of steps with bright or reflective tape
- Consider a ramp with handrails in to the home rather than steps
- Eliminate uneven surfaces or walkways, hoses, or other objects that may cause a person to trip or fall
- Restrict access to a swimming pool by fencing off with a **locked** gate
- Patio area, remove the fuel source and fire starters from any grills when not in use
- Make sure outside lighting is adequate. Light sensors that turn on lights automatically as you approach the house may be useful.
- Prune bushes and foliage well away from walkways or doorways
- Consider a NO SOLICITING sign for the front door.



## Home safety helpful hints

- Display emergency numbers and your home address near ALL telephones
- Install smoke alarms and carbon monoxide detectors near all sleeping areas and check their function and batteries on a regular basis
- Install secure locks on all outside doors and windows
- Hide a spare house key outside in the individual with dementia locks you out of the house
- Avoid the use of extension cords. Tack extension cords to the baseboards of a room to avoid tripping
- Cover unused outlets with childproof plugs
- Place red tape around floors, radiators, and other heating devices to deter the individual with dementia from standing on or touching a hot surface
- Check all rooms for acceptable lighting
- Stairways should have at least one handrail that extends beyond the first and last step
- Keep all medications (prescriptions and over the counter) locked
- Avoid clutter. Keep all walk areas free of furniture
- Keep plastic bags out of reach. An individual with dementia may choke or suffocate
- Remove all guns or other weapons from the home
- Lock all power tools and machinery in the garage, workroom or basement
- Remove all poisonous plants from the home





### **Is it safe to leave the person with dementia home alone?**

Each person is different; consider the following when making that decision

#### **Does the person with dementia:**

- Become confused or unpredictable under stress
- Recognize a dangerous situation
- Know how to use the telephone in an emergency
- Know how to get help
- Stay content within the home
- Wander and become disoriented
- Show signs of agitation, depression, or withdrawal when left alone for any period of time
- Attempt to do former interests or hobbies that might now require supervision, such as cooking or wood working

**As dementia progresses, these questions will need ongoing evaluation**

## Chapter 5: Activities



## Benefits of activities

**Activities are important for a person with dementia. They provide structure, purpose and meaning.**



Activities are the things we do, such as getting dressed, doing tasks, playing cards, or paying bills. They can be active or passive, done alone or with others. A person with memory loss doesn't have to give up the activities that he or she loves. Many activities can be changed to the person's ability. Activities reduce confusion, restlessness, apathy, and psychiatric signs such as delusions, hallucinations and paranoia.

|                                   |  |
|-----------------------------------|--|
| <b>People with dementia may:</b>  |  |
|                                   | Say no to activities   |
|                                   | Need activities to remain active   |
|                                   | Have a hard time with large groups of people                                   |
| <b>As the disease progresses:</b> |  |
|                                   | Keep in mind what activities the person can do and likes to do                 |
|                                   | Identify if the person can start an activity without help                      |
|                                   | Be aware of physical challenges (vision, hearing)                              |
|                                   | Focus on fun   |
|                                   | Encourage them to take part in daily life                                      |
|                                   | Consider tasks that are familiar (housekeeping, office work)                   |
|                                   | Think about the timing. Does the person do better in the morning or afternoon? |

## List of tips that help make an activity successful for the individual with dementia:

1. Make it simple-an activity should not require new learning
2. It should have minimal steps to complete
3. Make it personal-an activity should be meaningful to the person
4. Stress Free - the activity should not be tiring for the person
5. Successful-the activity should be focused around the personal needs and life

## Why encourage someone to participate in activities?

1. It promotes a time to experience positive emotions
2. It promotes a sense of purpose
3. It promotes a sense of belonging and self-esteem
4. It promotes the highest level of function

## Activities can:

1. Tap into past interest or skills (cards, house cleaning, arts and crafts, music, and exercise)
2. Be related to their past work history or experience
3. Be as simple as spending time talking or enjoying a snack together

Activities will need to be initiated by others as getting started is the most difficult task for person with dementia. The purpose of an activity is not in what is done, but in the doing of the activity. The process is more important than the end result.



## Planning the day

A planned day allows the person with dementia to spend time on activities that provide meaning and enjoyment.

### Before making a plan, consider:

- What the person likes and dislikes
- What are their strengths, skills and interests
- How the person used to spend his or her day
- What times of the day the person is at their best
- Allow plenty of time for meals, washing and dressing
- The person's regular times for getting up and going to bed

**Keep in mind as the memory loss continues, the abilities of a person will change.**

**Daily Planner** ☀️ 🕒 🚌 ⭐ 🚰 📖 **Date:** \_\_\_\_\_

|          |          |
|----------|----------|
| 7:00 AM  | 12:00 PM |
| 8:00 AM  | 1:00 PM  |
| 9:00 AM  | 2:00 PM  |
| 10:00 AM | 3:00 PM  |
| 11:00 AM | 4:00 PM  |

## Writing the plan

- What activities work best? What activities don't work well? Keep in mind that the success of an activity can vary from day to day.
- Are there times during the day when there is too much going on or too little to do?
- Are spontaneous activities enjoyable and easily completed?

Don't be concerned about filling every minute with an activity. The person with memory loss needs a balance of activity and rest.

|                  |  |   |
|------------------|--|---|
| <b>Morning</b>   |  |   |
|                  |  | Wash up, brush teeth, get dressed                             |
|                  |  | Make and eat breakfast  |
|                  |  | Have coffee, make conversation                                |
|                  |  | Discuss the paper, try a craft project, talk about old photos |
|                  |  | Take a break, have some quiet time                            |
|                  |  | Do some house work  |
|                  |  | Take a walk, play an active game                              |
| <b>Afternoon</b> |  |   |
|                  |  | Make and eat lunch, read mail, wash dishes                    |
|                  |  | Listen to music, do crossword puzzles, watch TV               |
|                  |  | Take a walk or visit a friend                                 |
| <b>Evening</b>   |  |   |
|                  |  | Make and eat dinner, clean kitchen                            |
|                  |  | Talk about things from the past over coffee and dessert       |
|                  |  | Play cards, watch a movie, give a massage                     |
|                  |  | Take a bath, get ready for bed, read a book                   |

Read more: <http://www.alz.org/care/dementia-creating-a-plan.asp#ixzz3eZDoFc9H>

## 50 Activities to do with an individual who has Alzheimer's disease

1. Clip coupons
2. Play favorite music and sing together
3. Rake leaves
4. Take a ride
5. Bake cookies
6. Take photos of the person and make a collage
7. Toss a ball
8. Sweep the patio
9. Blow bubbles
10. Take a walk
11. Color pictures
12. Make holiday cards
13. Do a simple puzzle
14. Sort coins
15. Pop popcorn
16. Read from a magazine
17. Model with play dough
18. Ask someone with a baby to visit
19. Weed the flower garden
20. Have an afternoon tea
21. Dye eggs
22. Give a manicure
23. Wash silverware and put away
24. Make a fresh fruit salad
25. Play dominos
26. Play a musical instrument
27. Put birdseed out for the birds
28. Make a frame out of popsicle sticks
29. Make homemade applesauce
30. Read classic short stories
31. Invite a neighbor or friend with a calm, pet to visit
32. Look at family photos
33. Roll yarn into a ball
34. Visit a family member
35. Eat a picnic lunch outside
36. Wash windows together
37. Ask the person about his first car
38. String cereal to hang outside for birds
39. Reminisce about the first day of school
40. Fold laundry or towels
41. Match a basket of socks
42. Cut pictures out of magazines or cards
43. Finger paint
44. Interview the person about his life
45. Remember great inventions
46. Recite nursery rhymes
47. Ask the person about his favorite pet
48. Pick flowers
49. Finish famous sayings
50. Create a small indoor garden in a box



## Chapter 6: Care Options



## Care options

|   |   |
|---|---|
| <b>Community Care Options</b>                 |   |
| Adult Day Center                              | Adult Day Center offer people with memory loss the opportunity to be social and to participate in activities in a safe environment  |
| Home Health Care                              | Home Health Care includes a wide range of services provided in the home, (homemaking, personal care, companion, lifeline) rather than in a facility. It can allow a person with memory loss to stay in his or her own home and can also help give the caregiver a break.  |
| <b>Residential Care Options</b>               |   |
| Assisted Living Facility                      | Assisted Living bridges the gap between living independently and living in a nursing home. Assisted living facilities offer housing, meals, supportive services and health care. Assisted Living residences generally provide 24 hour staff, recreational activities, housekeeping, laundry and transportation. Residents may choose which services they receive from the facility such as help with bathing, dressing, and eating or medication reminders. Costs vary depending on the services provided |
| Skilled Nursing Facility                      | Skilled Nursing Facility provide round the clock care and long term medical treatment. Most nursing homes have services and staff to address issues such as nutrition, care planning, recreation and medical care   |
| Continuing Care Retirement Communities (CCRC) | CCRCs provide different levels of care (independent, assisted living and nursing home) based on individual needs. A resident is able to move throughout the different levels of care within the community   |

## Choosing a care facility:

When you visit a residential care facility, ask to see the latest report from the state and the Special Care Unit Disclosure form. The facility is required to provide these. The report and the disclosure form can give you a picture of the facility's services.

Visit the facilities at different times of the day, including at meal times.

Ask how many rooms are available, the cost and what insurance can be used. Think about placing your name on a waiting list even if you are not ready to make a decision about a move.

If you will be paying privately for the facility, ask what happens if the person with memory loss runs out of money. Some facilities will accept Medicaid; others may not.

When making a decision on a care facility plan to visit and compare at least three facilities.



## Care facility checklist

|  |  |
|--|--|
| <b>Family Involvement</b>                        |  |
|  | Are family's parts of care planning and informed about changes in their loved one's condition and care needs?  |
|  | Can families communicate with staff about concerns and who in the facility should the family talk to about concerns?   |
| <b>Nursing facility staff</b>                    |  |
|  | Can the staff assist with personal care and address all medical needs?   |
|  | Does the staff know the likes and dislikes and have a good social history of person with memory loss so that care provided meets the individual's needs and interests? |
|  | Is the staff educated on caring for someone with memory loss/dementia?   |
| <b>Programs and Services</b>                     |  |
|  | Ask to see the activities calendar?  |
|  | Are activities available on the weekends and during evening time?  |
|  | Are activities designed to meet the like/dislikes of person with memory loss?  |
|  | Is transportation available for doctor's appointments?   |
| <b>Residents (person living in the facility)</b> |  |
|  | Do residents appear comfortable, relaxed and involved in activities?   |
|  | Do residents look neat, clean and dressed correctly for the time of year?  |

| <b>Environment</b> |   |
|--------------------|---|
|                    | Does indoor space allow for movement and promote independence?  |
|                    | Are indoor and outdoor areas safe and secure?   |
|                    | Is the facility easy to get around?   |
|                    | Is there a family visiting area?  |
|                    | Are resident's rooms clean?   |
|                    | Can residents bring personal items with them, such as: photos, blanket/sheets, chair?                             |
| <b>Meals</b>       |   |
|                    | Are there regular meal and snack times?   |
|                    | Is dining room pleasant?  |
|                    | Are family and friends able to join at mealtime?  |
|                    | Does the staff pay attention to make sure residents are getting enough food, drink and help with meals as needed? |
|                    | Are special diets provided?   |
|                    | Are there few distractions during meals (example: noisy TV or music)?   |
| <b>Rules</b>       |   |
|                    | Can family and friends participate in persons care and care plan meetings?  |
|                    | Do visiting hours work for the family?  |
|                    | Has discharge policy been discussed?  |

Resource: [http://www.alz.org/nyc/in\\_my\\_community17490.asp](http://www.alz.org/nyc/in_my_community17490.asp)

## Emergency planning for the *What Ifs*

It is important to have a plan in case of caregiver illness, disability, or death. Who will take care of your loved one with dementia if something happens to you?

### Tips to plan for urgent caregiving issues:

- Speak to a lawyer regarding a living trust, durable power of attorney for health care and finances, and other estate planning tools
- Talk with family about who will take responsibility for your family member with dementia
- Keep a notebook for the person who will be taking over the caregiving  
In the notebook include:
  - Emergency phone numbers
  - What are the present behavior concerns and likely solutions
  - Ways to calm the individual with dementia
  - What help is needed with toileting, feeding, or grooming
  - What are the person's favorite things to do and to eat
- Visit residential care facilities and get on the waiting lists in the event this type of care is needed in the future





## Caregiver qualities

**Caring for a person with a dementia is very hard and exhausting work. It has an impact on every aspect of your life. The role of the caregiver is a labor of love and benefits from specific qualities and emotions.**

### Caregiver qualities:

- Confidence –that I can do this
- Validation-that I feel valued for doing this
- Satisfaction-that I am doing good and feel good doing this

### Caregiving emotions:

- Empathy: the most important element of successful helping relationships. Empathy allows us to understand or feel what another person is experiencing from within the other person's viewpoint. It helps us see the world through their eyes and makes us consider the actions of others when we make decisions.
- Learn good coping skills by balancing the internal demands and stress that you put on yourself with the external demands that others may place on you.

**I Am A Caregiver.**

**I Try.**

**I Do.**

**I Hope.**

**I Care.**

eldercareissues.blogspot.com

**Although you have committed to being a caregiver you will notice that it also has unintentional consequences for you. It is important to recognize these effects and come to terms with them.**

**Unintentional consequences of caregiving:**

- You will notice that your social life and interactions have become limited
- You may have an increase in emotional and physical stress
- You may experience financial challenges
- You may notice changes in your own health

**What to do to help with consequences of caregiving:**

- Be open to learn new skills
- Become a part of a team
- Balance demands and resources
- Allow yourself to grieve



## The traits to be a good dementia caregiver

- Sense of humor
- Good eye contact
- Enjoys being a problem solver
- Creative
- Patient
- Interested in learning
- A good communicator
- Understands about relationship building
- Willing to be wrong, reevaluate, and try again

## The needs of the person with dementia

- To feel secure and safe
- To feel in control
- To feel loved and to love others
- To feel included

## How to build a caregiving relationship

- Understand the challenges the person with dementia faces
- Be aware and respect the person's habits and individuality
- Be aware of and respect the person's needs
- Appreciate what the person is able to do
- Structure the day to help with the person's challenges and support the remaining abilities

## How to make the relationship positive

- Build a trusting relationship
- Anticipate the person's needs
- Avoid rushing the person
- Use a calm voice-or be silent and wait
- Smile a lot
- Include the person in activities/decisions

## Things the family can do to help healthcare providers

You know your loved one the best. It is important to share everything you know with the members of the healthcare team to keep your loved one safe and comfortable.

- Discuss their likes and dislikes with the healthcare team
- Discuss their strengths
- Discuss your safety concerns and solutions that have worked
- Discuss what causes your loved one to become upset
- Discuss your family member's daily routines
- Provide a list of who to call with questions or concerns

**Remember:** Caregiving is a process; it develops and changes over time. Acknowledge your need for help and avoid burnout. Provide information to healthcare providers to help care for your family member.



## Introduction to my life tool

**This helpful tool is to be completed and shared with anyone who may provide medical or social care for you loved one with dementia. It will help the people interacting with your loved one in a more meaningful way.**

| <b>Name</b>                    |  |
|--------------------------------|--|
| What I liked to be called:     |  |
| My date of birth:              |  |
| My place of birth:             |  |
| My Family                      |  |
| My mother's name               |  |
| My father's name               |  |
| My sister's or brother's names |  |
|                                |  |
|                                |  |
|                                |  |
|                                |  |
| <b>My Childhood:</b>           |  |
| Memories from school:          |  |
|                                |  |
| My home where I grew up        |  |
|                                |  |
| <b>My working life:</b>        |  |
| First Job:                     |  |
|                                |  |
| Other jobs:                    |  |
|                                |  |
| Any memories about work        |  |
|                                |  |

|                                       |   |
|---------------------------------------|---|
| <b>Important people in my life</b>    |   |
|                                       |   |
| <b>My spouse's name ( if married)</b> |   |
| <b>Names of children( if any)</b>     |   |
|                                       |   |
|                                       |   |
| <b>My favorite things</b>             |   |
| Favorite Places                       |   |
| Favorite Holidays                     |   |
| Favorite hobbies                      |   |
| Favorite places/vacations             |   |
| Favorite activities                   |   |
| <b>I enjoy:</b>                       | <b>circle</b> Inside activities      outside activities   |
| <b>I would rather participate:</b>    | <b>circle</b> Group activities      individual activities |
| Favorite Foods                        |   |
|                                       |   |
|                                       |   |

|                                    |  |
|------------------------------------|--|
| Favorite television/radio shows    |  |
|                                    |  |
| <b>My life now</b>                 |  |
| Sleep/ Wake                        | Time I usually wake up                     |
|                                    | Nap times                                  |
|                                    | Time I go to bed                           |
|                                    | My side of the bed                         |
| <b>Self-care</b>                   |  |
| Routine                            | Bathing                                    |
|                                    | Dressing                                   |
|                                    | Teeth                                      |
|                                    | Makeup                                     |
|                                    | Shave                                      |
|                                    | Take Medications                           |
|                                    | Coffee/tea                                 |
|                                    | Use the bathroom                           |
|                                    | Read the paper or watch TV                 |
| <b>Bathing preferences: circle</b> | Shower      Sponge bath      Tub           |
|                                    | Morning      afternoon<br>Evening          |
|                                    | Daily      every other day      weekly     |
| Toileting:                         |  |
| Do you get up during the night?    |  |
| How many times a day               |  |
| <b>What I sleep in? circle</b>     | Nude      underwear      PJs<br>Night gown |
| Eating                             | Breakfast      Lunch<br>Dinner             |
| Foods I don't like                 |  |
|                                    |  |
|                                    |  |
| <b>I feed myself: circle</b>       | Left hand      Right hand                  |
| <b>I prefer to drink: circle</b>   | Before      with      after      my meal   |

|   |               |              |         |
|---|---------------|--------------|---------|
| <b>I use assisted devices:</b>                  | <b>circle</b> | Crutches     | Cane    |
|   | Walker        | Wheelchair   |         |
|   | dentures      | hearing aids | glasses |
| Additional information you should know about me |               |              |         |

## Positive approaches to caregiving

In the world of dementia, **“AS IS”** is a good phrase to describe a mindset. **An “AS IS” mindset frees family members to thoroughly enjoy their loved one...to live in the moment...to observe small details of what their loved one is doing and to be patient with their loved one.**

### **Don’t argue a point**

Arguments among family members over the care usually only raise emotions and rekindle unresolved issues or conflict. Open a discussion about the issue and allow family members to add ideas on a best way to handle it. Remember: *“none of us is as smart as all of us.”*

### **Be open to new learning**

If you are seeking new information, you’ll find it. If you’re closed to new ideas, you won’t hear any. Education empowers us to feel more confident!

### **Is “Self” in the way?**

**Always challenge your thinking by asking yourself, “Why do I want this?”** if the answers come back **“I would be embarrassed if my mom’s clothes don’t match”** or **“what would people think (of me) if my husband couldn’t remember the names of those who visit him.”** Think instead- **What would your loved one want?**

Keep your eyes on the journey ahead. Keep focused and learn what you can to help with the care needs. All persons with dementia are unique and have different needs depending on the disease process, previous education, personality, and interests.



Designed by The Edcon Group, Kansas City, MO

## Grief cycle in dementia caregiving

Grief plays a huge part in the perception of the burden of caregiving. Grief must be acknowledged and discussed to be decreased and to come to terms with the burden.

### The caregiver may:

- Deny the changes in the person
- Push person to be the “old self”
- Acknowledge the changes and express feelings about it
- Grieve with anger or sadness
- Accept and enjoy the person as they are now
- Appreciate the effort the person makes to make sense of the world

### How to heal caregiver grief:

- Accept your new reality that your loved one has dementia
- Identify the diagnoses as a loss
- Know the common symptoms of grief
- Identify that your feelings are important
- Ask for help
- Be kind to yourself
- Create room for hope
- Confront your fears
- Seek the spiritual

**Be in the moment. Live with meaning and purpose – know what really matters to you**



Matters of the Mind and the Heart by Beverly L. Moore, RN, CS, 200  
When someone you care about has Alzheimer's by Alan D. Wolfelt, Ph.D. and Kirby J. Duvall, M.D., 2011

## Ways to stop guilt from dementia care



Caregiving can be very rewarding; it is also hard work and can be extremely stressful. Some of the emotions that arise, such as grief and anger, are healthy responses to challenging circumstances. These emotions can be useful, helping you to move forward. But other emotions, such as guilt, can be unhelpful, leaving you feeling powerless or “stuck”.

Caregivers often feel guilty, even if others are reassuring them that they are doing the best they can. Guilt is a tiring emotion. It can use energy a caregiver needs to complete other tasks.

One of the unique aspects of caring for someone with a dementia is that caregivers almost always feel guilty in some way. This has been labeled as unjust guilt. The unjust guilt is usually caused by the demands of the caregiver role and the expectations that you and others put on yourself. The feeling of guilt is normal however, there are ways to help reduce the unjust guilt and move through these feelings.

### **When feeling guilt, remember:**

- Acknowledge your feelings
- Give yourself credit-You are doing the best you can in this situation
- Understand that changes in your loved one’s behavior is part of the disease
- Develop and have realistic expectations
- Change your expectations as the disease progresses
- Accept your loved one’s new behaviors and the loss of social skills
- Remember: caregiving is about love

### **What to do to overcome guilt**

1. Identify the guilt and determine where these feelings come from
2. Realize that you are not alone in feeling this way
3. Find ways to develop positivity and to be more forgiving of yourself

## Normal feelings and concerns caregivers have that lead to feelings of guilt

### **How you treated the person before the diagnoses**

- You did not know the person had a dementia, causing the behaviors that upset you.

### **At times you don't like the person you are caring for**

- These are normal feelings and you cannot help your feelings. However you have the ability to control how you respond.

### **You would like more time for yourself**

- Everyone experiences this need. It is very important for caregivers to enjoy time away to stay healthy.

### **You feel you should be able to manage this role with no help**

- Ask yourself if your expectations are realistic? Accepting outside help benefits both the caregiver and the person with dementia.

### **You decide the person needs to move into a nursing facility**

- Remind yourself that you have not failed your loved one and you are still needed.



## Ten real-life strategies for dementia caregiving

As caregivers, we often use instinct to help us decide what to do. No one ever gave us lessons on how to relate to someone with memory loss. Unfortunately, dealing with Alzheimer's disease and other dementias is difficult and often the right thing to do does not always work. Here is some practical advice:

1. **Being Reasonable, Rational and Logical Will Just Get You into Trouble.** When someone is acting in ways that don't make sense, we tend to carefully explain the situation, thinking this will help get the reaction we feel is appropriate. However, the change in the person with dementia's brain doesn't allow him or her to have the logical and rational thought process we expect. You will notice that he or she does not respond to our explanations, no matter how logical. What to do in this scenario: use straightforward, simple sentences.
2. **People With Dementia Do Not Need to Be Grounded in Reality.** When someone has memory loss, they often forget important events that happened in their life such as the passing of a parent. When we remind him of this loss, we also remind him of that pain. Many times a person with dementia will state he wants to go home. When we reassure him that he is at home it often leads to an argument. Attempting to redirect him by asking him to tell you about his home is a technique that can calm a person with dementia.
3. **You Cannot Be a Perfect Caregiver.** Just as there is no such thing as a perfect parent, there is no such thing as a perfect caregiver. You have the right to the full range of human emotions. At times you are going to be frustrated and impatient. These feelings are normal. Learn to forgive your loved one as well as yourself is essential in the caregiving journey.

4. **Therapeutic “Fiblets” Reduces Stress.** We tend to be overly honest with people. *However, when someone has dementia, honesty can lead to distress for both of you. Ask yourself- Does it really matter that your loved one thinks she is the volunteer at the day care center? Is it okay to tell her that the two of you are going out to lunch and then “coincidentally” stop by the doctor’s office on the way home to pick something up as a way to get her to the doctor? We are raised to speak the truth and therapeutic filets may cause an ethical dilemma for some caregivers, however if a truthful response causes emotional distress over and over again or a lack of medical care it is better to use a therapeutic fiblet to spare your loved one the emotional or physical pain.*
5. **Making Agreements Doesn’t Work.** Your loved one has very poor short term memory. If you ask him not to do something ever again, or to remember to do something, it will soon be forgotten. They aren’t capable of this type of memory retention. For people in early stage dementia, leaving notes as reminders can sometimes help, but as the disease progresses, this will not work. Taking action, rather than talking and discussing, is usually a more successful approach. For example, getting a teakettle with an automatic “off” switch is better than warning someone of the dangers of leaving the stove on.
6. **Doctors Often Need You To Educate Them.** Telling the doctor what you see at home is important. The doctor can’t tell during an examination that your loved stays up all night pacing. Sometimes doctors, too, need to deal with therapeutic fiblets to help their patients feel better. For example, telling the patient that an antidepressant is for memory rather than depression.

7. **You Can't Do It All.** It's OK to Accept Help Before You Get Desperate. When people offer to help, you should always say "YES." Have a list of things people can do to help you, whether it is bringing a meal, picking up a prescription, helping trim the roses or staying with your loved one while you run an errand. It is harder to ask for help than to accept it when it is offered, so don't wait until you "really need it" to get support.
8. **It is Easy to Both Overestimate and Underestimate What Your Loved One Can Do.** It is often easier to do something for our loved ones than to let them do it for themselves. However, if we do it for them, they will lose the ability to be independent in that skill. On the other hand, if we insist individuals do something for themselves and they get frustrated, we just make our loved one's agitated and most likely haven't increased their abilities to perform tasks. It is a constant juggle to find the balance and that balance may shift from day to day.
9. **Tell, Don't Ask.** Asking "What would you like for dinner?" may have been a perfectly normal question at another time. But now we are asking our loved one to come up with an answer when he or she might not have the words for what they want. Saying "We are going to eat now" encourages the person to eat and doesn't put them in the dilemma of having failed to respond.
10. **It Is Perfectly Normal to Question the Diagnosis When Someone Has Moments of Lucidity.** One of the hardest things to do is to remember that we are responding to a disease, not the person who once was. Everyone with dementia has times when they make perfect sense and can respond appropriately. We often feel like that person has been faking it or that we have been exaggerating the problem when these moments occur. We are not imagining things—they are just having one of those moments, to be treasured when they occur.

**Caregiver stress is the emotional and physical strain of caregiving. Stress can affect your body, your thoughts and feelings, and your behavior.**

## **10 Signs of caregiver stress**

1. Denial about the disease and its effect on the person who's been diagnosed.

*I know Mom's going to get better.*

2. Anger at the person with Alzheimer's or others; that no effective treatments or cures currently exist; and that people don't understand what's going on.

*If he asks me that question one more time, I'll scream!*

3. Social withdrawal from friends and activities that once brought pleasure.

*I don't care about getting together with the neighbors any more.*

4. Anxiety about facing another day and what the future holds.

*What happens when he or she needs more care than I can provide?*

5. Depression begins to break your spirit and affects your ability to cope.

*I don't care anymore.*

6. Exhaustion makes it nearly impossible to complete necessary daily tasks.

*I'm too tired for this.*

7. Sleeplessness caused by a never-ending list of concerns.

*What if she wanders out of the house or falls and hurts herself?*

8. Irritability leads to moodiness and triggers negative responses and reactions

*Leave me alone!*

9. Lack of concentration makes it difficult to perform familiar tasks.

*I was so busy; I forgot we had an appointment.*

10. Health problems begin to take their toll, both mentally and physically.

*I can't remember the last time I felt really good.*

If you experience several of these stress symptoms on a regular basis, consult a physician or call the Alzheimer's Association to help you manage the stress in your life. Courtesy National Alzheimer's Association

## Tips for coping/managing stress as a caregiver

### 1. Educate yourself about the disease

- Search out sources of information from your physician, libraries, internet, CT Center for Health Aging, etc.
- Set realistic expectations for both yourself and the person with the disease based on your understanding of the disease.

### 2. Take care of yourself

- To avoid “burn out,” take time for yourself
- Attend to your own health care needs, i.e., exercise, eat right, get enough sleep, avoid use of alcohol and pills as aids to reducing stress
- Keep your sense of humor
- Participate in activities you enjoy
- Reward yourself

### 3. Learn to *Let it Go*

- Simplify your lifestyle to protect your time and energy for what’s most important
- Accept that you may not be able to do things the way you use to

### 4. Practice stress-reduction techniques such as:

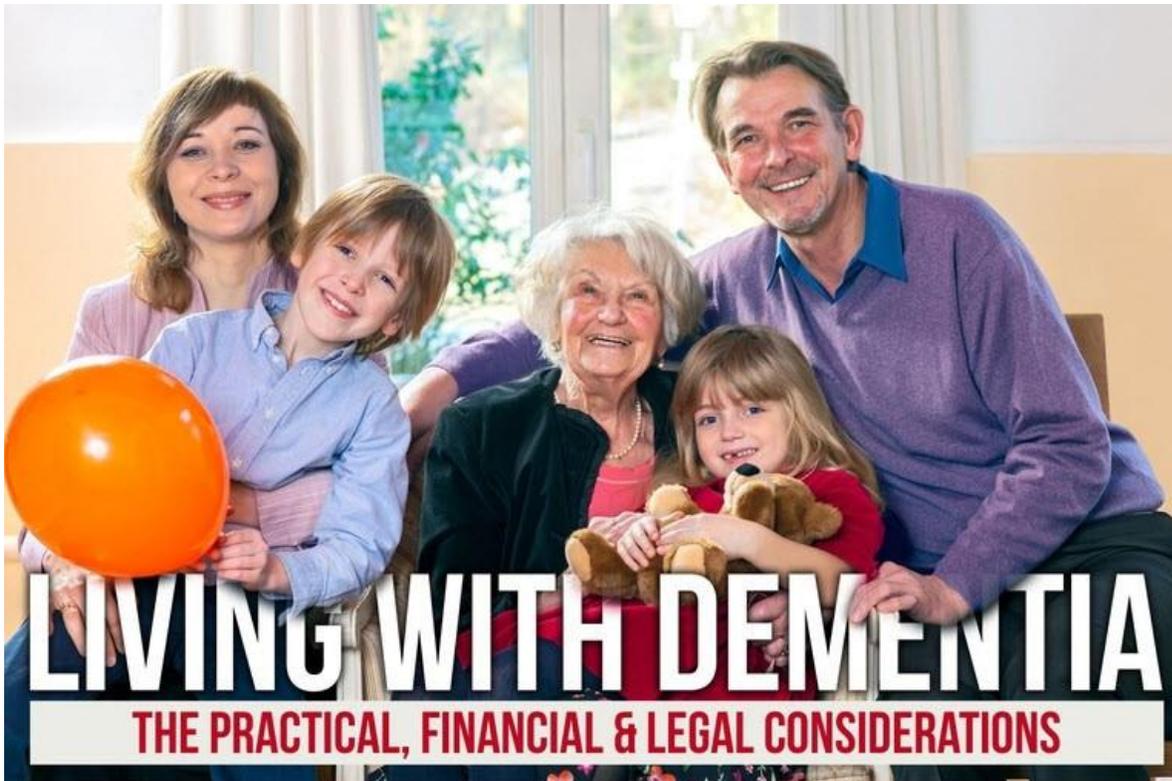
- Deep breathing, Meditation
- Exercise
- Listen to music

### 5. Ask for help

- Present family and friends with ways in which they can assist you
- Explore available community resources



## Chapter 8: Legal and Financial Concerns



## Plan ahead: legal and money concerns

### Get started by putting all of your information in place

|                            |   |
|----------------------------|---|
| <b>Official papers</b>     |   |
|                            | Living Will   |
|                            | Durable Power of Attorney for Health Care and Finances      |
|                            | Will  |
| <b>Money documents</b>     |   |
|                            | Bank account information                                    |
|                            | Deeds, mortgage papers, ownership statements                |
|                            | Monthly outstanding bills                                   |
|                            | Retirement benefit summaries                                |
|                            | Social Security and Pension Income                          |
|                            | Stock and bond certificates                                 |
| <b>Costs you may face:</b> |   |
|                            | Ongoing medical treatment for dementia and other conditions |
|                            | Medical equipment   |
|                            | Safety-related expenses, such as home safety changes        |
|                            | Medications   |
|                            | Adult day services  |
|                            | In-home care services                                       |
|                            | Assisted Living Facility                                    |
|                            | Skilled Nursing Facility                                    |
|                            | Insurance Premiums  |
|                            | Medicare and Medicaid co-pays                               |
|                            | Medicare Part D Premium                                     |
|                            | Legal documents   |

| <b>Assistance in your area</b> |   |
|--------------------------------|---|
|                                | Connecticut Center for Health Aging<br>1-800-273-0078 |
|                                | Alzheimer's Association<br>1-800-272-3900             |
|                                | Area Agency on Aging<br>1-800-994-9422                |
|                                | Call 211  |
|                                | 211ct.org   |



Resource: <http://www.alz.org/care/alzheimers-dementia-financial-legal-planning.asp>

## Overview of medical, legal, and financial planning documents

| <b>Medical Documents</b>                  | <b>How it is used</b>  |
|---|--|
| Living Will                               | Describes and instructs how the person wants end-of-life health care managed   |
| Durable Power of Attorney for Health Care | Gives a designated person the authority to make health care decisions on behalf of the person with Alzheimer's disease   |
| Do NOT Resuscitate Form                   | Instructs health care professionals not to perform CPR in case of the heart stops or breathing stops   |
| <b>Legal/Financial Documents</b>          | <b>How it is used</b>  |
| Will                                      | Indicates how a person's assets and estate will be distributed among beneficiaries after his/her death   |
| Durable Power of Attorney for finances    | Gives a designated person the authority to make legal/financial decisions on behalf of the person with Alzheimer's disease   |
| Living Trust                              | Gives a designated person (trustee) the authority to hold and distribute property and funds for the person with Alzheimer's disease  |
| Guardianship/conservatorship              | <p>If a person can NO longer make his or her own financial and /or health care decisions, someone else may have to become the person's guardian (also known as a conservator in some US states)</p> <p>A guardian or conservator is appointed by a court to make decisions about the person's care and property, when it finds that a person is legally incapacitated.</p> <p>In the case of dementia and its effect on the brain, legal incapacity refers to the person's inability to make rational decisions about his or her care or property.</p> |

## Appendix

### Books to help caregivers understand Alzheimer's and related dementias

*Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease* By: Joanne Koenig Coste and Robert Butler

*The 36 Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease, Related Dementias, and Memories* By: Nancy L. Mace and Peter V. Rabins

*Creating Moments of Joy for the Person with Alzheimer's Disease or Dementia: A journal for Caregivers, Fourth Edition* By Jolene Brackey

*On Pluto: Inside the Mind of Alzheimer's* By Greg O'Brien and Lisa Genova

*Understand Alzheimer's: A First-Time Caregiver's Plan to Understand and Prepare for Alzheimer's & dementia* By: Calistoga Press

*Alzheimer's Early Stages: First Steps for Family, Friends, and Caregivers* By Daniel Kuhn and David A. Bennett

*Chicken Soup for the Soul: Living with Alzheimers & other Dementias: Stories of Caregiving, Coping and Compassion*, By Amy Newmark and Angela Timashenka Geiger

*The Best Friends Book of Alzheimer's Activities and Best Friends Book of Alzheimer's Activities Volume Two* By Virginia Bell and David Troxel

*A Dignified Life: The Best Friends Approach to Alzheimer's Care: A Guide for Care Partners* By Virginia Bell and David Troxel

*The Little Book for Alzheimer's Caregivers* By Celia Koudele

*Jan's Story: Love Lost to the Long Goodbye of Alzheimer's* By Barry Petersen and Katie Couric

*Still Alice* By Lisa Genova

*Coach Broyles' Playbook for Alzheimer's Caregivers: A Practical Tips Guide* By Frank Broyles

*Through the Seasons: An Activity Book for Memory-Challenged Adults and Caregivers* By Cynthia R. Green, Joan Beloff

*Matters of the Mind and the Heart* By Beverly L. Moore

## Books to help children understand Alzheimer's and related dementias

*Always my Grandpa: A story for Children about Alzheimer's Disease* By: Linda Scacco, Ph. D and Nicole E. Wong

*Still My Grandma* By Vronique Van den Abeele

*The Memory Box* By Mary Bahr and David Cunningham

*Curveball: The Year I Lost my Grip* By: Jordan Sonnenblick

*Allie Learns about Alzheimer's Disease: A Family Story about Love, Patience and Acceptance* By: Kim Gosselin and Tom Dineen

*What's Happening to Grampa?* By: Maria Shriver

*The Graduation of Jake Moon* By: Barbara Park

*Wilford Gordon McDonald Patridge* By: By Mem Fox, illustrated by Julie Vivas

### Children's book on line:

*Grandma's Cobweb*

[www.alzheimershope.com/grandmascobwebs/inmemory.php](http://www.alzheimershope.com/grandmascobwebs/inmemory.php)

## **Dementia Internet Resources**

### **Alzheimer's Foundation of America (AFA)**

<http://alzfdn.org/>

Provides care and support to individuals with Alzheimer's disease and related dementias, and their caregivers

### **Alzheimer's Disease Education and Referral Center (ADEAR)**

[www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)

Developed by the National Institute of Aging and is a wonderful site full of information about current research, available publications, and referral sources

### **Alzheimer's Association**

[www.alz.org](http://www.alz.org)

Alzheimer's Association national site and has information on Alzheimer's disease and dementia symptoms, diagnosis, stages, treatment, care and support resources

### **Medline Plus: Alzheimer's disease**

[www.nlm.nih.gov/medlineplus/alzheimersdisease.html](http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html)

### **Clinical Trials**

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

National Institutes of Health current clinical trials in Alzheimer's disease

### **New York Online Access to Health (NOAH)**

<http://www.noah-health.org/>

NOAH has extensive links and information related to normal aging as well as Alzheimer's disease

### **Mayo Clinic Research Center**

[www.mayoclinic.com/health/alzheimers/AZ9999](http://www.mayoclinic.com/health/alzheimers/AZ9999)

### **Lewy Body Association**

[www.lbda.org/](http://www.lbda.org/)

Raises awareness of the Lewy body dementias (LBD), supporting people with LBD, their families and caregivers and promoting scientific advances

### **The Association for Frontotemporal Degeneration**

[www.theaftd.org/](http://www.theaftd.org/)

Raises awareness of the Frontotemporal Degeneration dementias (FTD), supporting people with FTD, their families and caregivers and promoting scientific advances

### **The Murray Alzheimer Research and Education Program (MAREP)**

[www.marep.uwaterloo.ca](http://www.marep.uwaterloo.ca)

An innovative program that integrates research and educational activities in an effort to improve dementia care

**Dementia Caregiver resource Guide created and developed by:  
Michelle Wyman, LSW and Patty O'Brian**



*Center locations located within The Hospital of Central Connecticut, Bradley  
and New Britain General campuses and MidState Medical Center.*

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Connecticut any time. Multilingual assistance and TDD also available.*