

Dementia Care Partner **Resource Guide**

Hartford HealthCare
Center for Healthy Aging

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Welcome

This book has been thoughtfully created for you, the care partner. Caring for an individual with this disease is not intuitive. Being a care partner can be challenging and overwhelming at times. This guide is meant to serve as a road map to help you navigate those challenges and anticipate changing needs so that you can recognize and appreciate the moments of joy.

Throughout this book we refer to you as a care partner. We acknowledge that individuals with dementia can require a great deal of care and our hope is that partnering with them to ensure they are getting the appropriate level of care fosters their independence and allows them to live a life with dignity.

We hope that you find this publication helpful and know that the Hartford HealthCare Center for Healthy Aging is here to partner with you.

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Table of contents

Chapter 1: Introduction to Dementia

What is dementia? 6
Why get a diagnosis? 9
How can I find out if I have dementia? 9
The healthy brain 10
What happens to the brain with dementia? 11
Symptoms and stages of dementia 11
The brain – normal functioning and impaired functioning with dementia 12

Chapter 2: Younger Onset Dementia

Why get a diagnosis 15
Work and younger onset dementia 15
What about social supports? 16
Strategies for couples 17
Strategies for children 17
What can you do? 17

Chapter 3: Communication

The basics of good communication 19
Ensuring a positive connection 20
Creative communication techniques 20
How to complete a care task 21
Communication through the stages of dementia 22
Ten tips for effective communication with a person living with dementia 25

Chapter 4: Understanding Behaviors Related to Dementia

Understanding behaviors (the way people behave or act) 27
What behaviors can be linked to dementia? 28
Managing personality and behavior problems 29
Five common behaviors that occur with dementia and what to do 30
Inappropriate sexual behavior 31
Responding to a challenging behavior 32
Catastrophic reaction 33
How can a catastrophic reaction be prevented? 34
Wandering 35
Basic human needs and the language of behavior 37

Chapter 5: Safety

General safety concerns for people living with dementia 39
Safety in the physical environment 39
Home Safety: Room to room 42
Is it safe to leave the person living with dementia home alone? 46
Driving safety 47

Chapter 6: Activities

Benefits of activities 50
Tips to help make an activity successful for the individual with dementia 51
Planning the day 51
Writing the plan 52
Activities to do with an individual who has dementia 53

Chapter 7: Care Options

Care options 55
Choosing a care facility 56
Care facility checklist 57
How you can partner with rehabilitation 58
Emergency planning for the "What ifs" 59

Chapter 8: I'm a Care Partner, now what?

Care partner qualities 61
The traits to be a good dementia care partner 62
How to partner with your healthcare providers 63
"Introduction to my life" tool 64
Positive approaches to being a care partner 67
Grief cycle in being a dementia care partner 68
Ways to stop guilt from dementia care 69
Normal feelings and concerns care partners have that lead to feelings of guilt 70
Ten real-life strategies for a dementia care partner 71
Ten signs of care partner stress 74
Tips for coping/managing stress as a care partner 75

Chapter 9: Legal and Financial Concerns

Plan ahead: legal and money concerns 77
Overview of medical, legal, and financial planning documents 78

Appendix and Glossary

Books to help caregivers understand Alzheimer's and related dementias 80
Books to help children understand Alzheimer's and related dementias 83
Dementia internet resources 86

CHAPTER 1

Introduction to Dementia





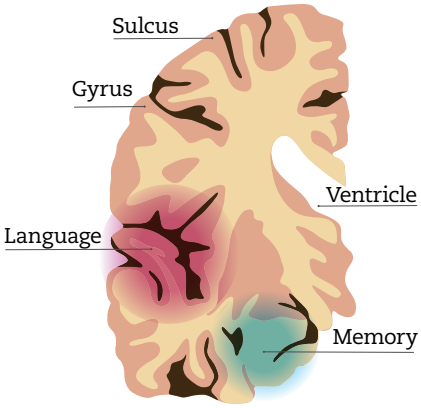
What is Dementia?

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.

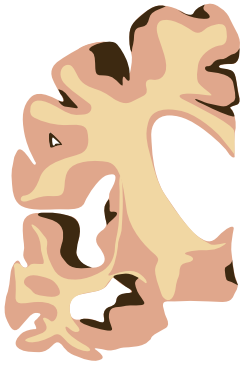
Symptoms

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

NORMAL BRAIN
(cross-section)



ALZHEIMER'S BRAIN
(cross-section)



Most common types of dementia

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

Alzheimer's disease, often abbreviated AD. 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. 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 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 loss, personality changes, speech and language problems

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 such as age, family history, and genetics that increase the likelihood of developing Alzheimer's.

Vascular dementia, often abbreviated VaD. Vascular dementia is caused by conditions that block or reduce blood flow to different areas of the brain. This causes the brain to get less oxygen and nutrients. It often presents as general confusion, agitation, poor judgment, problems with reasoning, and changes in behaviors. Heart disease, stroke, diabetes, high blood pressure, high cholesterol and smoking increase the risk for vascular dementia.

Acquired brain injury, often abbreviated ABI is caused when there is some type of injury or lack of oxygen to the brain. Dementia-related symptoms in brain injury often affect thinking, ability to concentrate, memory, communication, personality, mood, behaviors and interactions with others.

Fronto-temporal dementia, often abbreviated FTD. Frontotemporal Dementia is caused by a group of disorders that occur when nerve cells in the frontal and temporal lobes of the brain are lost. This causes the

lobes to shrink. It often presents as changes in behavior, personality, language (speech), poor planning and judgment and certain types of movement.

Dementia with Lewy Body, often abbreviated LBD. Lewy body dementia is caused by abnormal deposits of a protein in the brain. It often presents as hallucinations, apathy (loss of motivation, interest, and concern), movement disorders and changes in sleep patterns. It leads to a decline in thinking, reasoning and motor skills.

Wernicke-Korsakoff Syndome, often abbreviated WKS, Wernicke-Korsakoff Syndrome is a brain disorder caused by a lack of vitamin b1 or thiamine, long term alcohol abuse can increase the chance of this diagnosis. It often presents with confusion, changes in eyes and vision and creative storytelling.

Cretzfeldt-Jacob disease, often abbreviated CJD, and referred to as Mad Cow Disease. Creutzfeldt-Jakob Disease destroys brain cells creating sponge-like holes or lesions in the brain. It often presents with difficulty controlling body movements such as sudden jerky movements, difficulty speaking, insomnia, vision changes, memory loss, impaired thinking.

Parkinson's disease dementia, often abbreviated as PDD. The cause of Parkinson's disease dementia is currently unclear. It often presents as memory loss, difficulty concentrating, loss of decision making ability, disorientation to familiar surroundings, trouble with speaking and understanding complex language. It's important to know that not all people with Parkinson's disease get dementia.

Mixed Dementia, this is a combination of two types of dementia. The most common combination is Alzheimer's disease and vascular dementia. The second most common is Alzheimer's disease and Lewy Body dementia.

Chronic Traumatic Encephalopathy, often abbreviated as CTE. The greatest risk factor for Chronic Traumatic Encephalopathy is repetitive brain trauma. Repeated blows to the head in sports, frequent concussions, uncontrolled epilepsy or physical trauma to the head. This disease causes brain damage and common symptoms are short-term memory loss, confusion, changes in personality, unpredictable impulsive behavior, and difficulty with balance 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. A doctor will determine what tests are needed to identify the reason for the memory issues.

Treatable conditions that may be causing your memory loss

- Medication side effects
- Thyroid, kidney or liver disorders
- Vitamin B12 deficiency
- Brain tumor
- Depression
- Lyme disease
- Delirium

What are the advantages to an early diagnosis?

- 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.)

How can I find out if my loved one has dementia?

The first step is to make an appointment with their primary care provider for a physical exam and discuss the concerns and symptoms. Be sure to be there as their support person. This will help to make sure your questions and concerns are being addressed.

During the doctor's visit talk about:

Health concerns

Discuss what brought you and your loved one to the doctor and any fears or concerns you may have.

Medications

Bring a list of all your medications from the doctor and all over-the-counter medications.

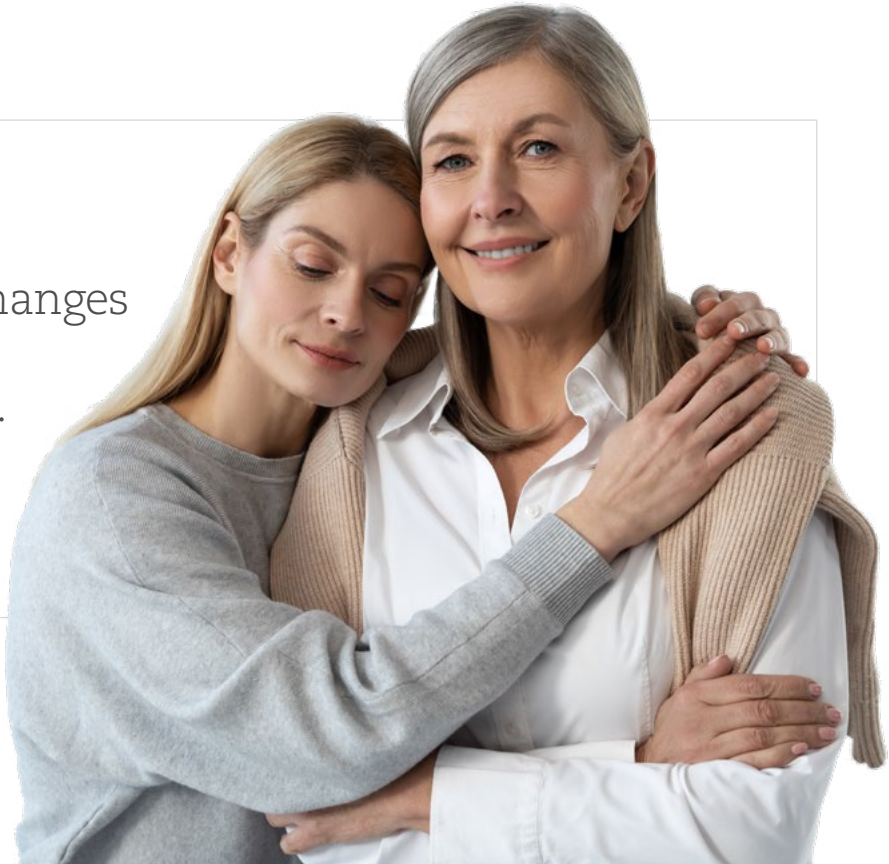
What to expect at your doctor appointment

- 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 dementia, the brain changes causing these tasks to become more difficult.



What happens to the brain of a person living with dementia?

Symptoms and stages of dementia

Ability Affected	Early Stage	Middle Stage	Late Stage
Memory	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 a 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
Cognitive Ability	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 one-step instruction to complete tasks	Has little noticeable cognitive function; shows poor judgment; loses sense of time and place
Motor Skills	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
Mood and Behavior	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 being suspicious and delusions or compulsive actions	Is often agitated; may not recognize primary caregiver; lose awareness of recent experiences as well as of their surroundings
Ability to complete personal care	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
Language	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 limited 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

Each part of the brain has a function and depending on where the dementia is located in the brain different challenges will occur. The person living with dementia will have impaired functioning and the care partner 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
Hippocampus	Involved in storing recent memories Sensory information is received and placed into storage for later retrieval	Unable to store new information Gets lost easily Repeats questions Is confused No sense of time Loses possessions	Provide eye contact Validate feelings Answer questions as if they were heard for the first time Redirect to non-confusing activities
Frontal Lobe	Involved in planning, decision making and purposeful behavior Personality, judgment, attention span Regulates mood Controls impulses and social appropriateness	Cannot plan, initiate or carry out complex activities Problems with new situations Easily distracted Personality changes common	Give step by step directions one at a time Give prompts, visual cues to start an activity Keep environment safe Reduce environmental stimuli and noise levels
Occipital Lobe	Receives and processes visual information from the eyes Analyzes visual information for orientation, position, and movement	Unable to process rapid body movements Loses sense for 3-dimensional space Loses peripheral vision	Always approach from the front Avoid patterned floor and wall designs Assist with slow and deliberate movements
Temporal Lobe	Responsible for perception Processes language and ability to speak and understand language Puts together the parts to make sense	Develops aphasia - an impairment resulting in an inability to make oneself understood or to understand others Examples: word loss, disorganized sentences, make up answers to cover up word deficit	Early on – fill in missing words Later on – prompt with gestures, body language, hand-on-hand or visual cues Use positive body language
Parietal Lobe	Sensory perceptual part of the brain Processes sensations such as pain, touch, heat Words put together into thoughts	Develops agnosia - cannot make sense of the senses, misidentifies familiar objects, and does not understand their purpose Cannot follow auditory and visual cues	Assist with prompts, gestures, demonstration and body language Give visual cues that help clarify the purpose or goal of an object

CHAPTER 2

Younger Onset Dementia



Younger Onset Dementia is a term used for people who develop dementia under the age of 65. Many of these people have symptoms in their 40s and 50s. Alzheimer's disease and Frontotemporal dementia are thought to be the most common forms of dementia for people with younger onset.

The symptoms of dementia are not determined by a person's age, but younger people often have different needs, and require different support. It can be difficult to accept this diagnosis because many people relate dementia to older people. Since this diagnosis is given earlier in their life they are likely to be physically and socially active, which brings new challenges.

At the time of diagnosis they may be:

- In full-time employment
- Actively raising a young family
- Caring for aging parents
- Financially responsible for a family
- Physically strong and healthy

For these reasons people with younger-onset dementia may face unique challenges:

- Stigmas and stereotypes about the disease
- Due to their young age, people may not believe they have the disease or question the diagnosis
- They may lose relationships or jobs because people don't understand that dementia can affect young people
- Some people don't understand that dementia is a medical illness
- Face new financial challenges related to steady income and ability to work



Why get a diagnosis?

Getting a diagnosis early is very important. It provides treatment options including the opportunity to participate in clinical trials. Medications are available to lessen the symptoms for a limited time, giving you a chance to plan for the future. Diagnosis helps identify personal health concerns and lifestyle changes that may preserve cognitive function. Including lifestyle changes such as:

- Quitting smoking
- Blood pressure control
- Diabetic management
- Better sleep
- Increased physical activity

Work and younger onset dementia

Younger people with dementia are more likely to be employed at the time of diagnosis, have dependent children, be physically active and have financial commitments.

The care partner and the person living with dementia may want to talk with their employers before the condition noticeably affects job performance and attendance.

Be aware of potential effects of discussing the diagnosis, consider consulting with an employment law attorney.

It is important to secure the benefits to which you are entitled.

Some things to consider when talking to the employer:

- Is early retirement an option?
- Is there another position available in the company that would be better suited for the evolving needs and limitations?
- What are you and your loved one's benefits?
- Does the employer offer an Employee Assistance Program (EAP)? If so, this is a great place to start to discuss available options.
- What resources and benefits are available under Americans with Disabilities Act, Family and Medical Leave Act and COBRA?

People with younger onset dementia will eventually be unable to work and this loss of income is often a serious concern. A spousal care partner may also quit their job or decrease work hours, which increases financial strain. Consider talking to a financial advisor and/or an elder law attorney to help plan for future financial needs.

Be mindful of risks associated with the type of work and assess if it is still safe to continue working.

It's important not to make rash decisions that could affect one's overall health and financial well-being. Become educated on options and access to employee benefits.

What about social supports?

Some medical benefits and many social-support programs in Connecticut don't provide assistance unless the person with dementia is older than age 65. Younger people may need special waivers to get into these programs.

What can be done?

- Talk with a financial planner and an attorney to help plan for future financial needs
- Explore what benefits may be available through Social Security, Medicare, or Medicaid
- Organize financial documents to manage your family's finances
- Make a list of username and password information
- Complete Power of Attorney forms (financial and medical) as soon as the diagnosis is made to assist with planning as the disease progresses
- Develop an Advance Directive/Living Will
- Create a folder/personal health record that has a list of doctors, tests, important medical information and resources for the person living with dementia
- If a family member (adult or young child) is struggling to accept and understand younger onset dementia there is a list of books and videos available at the back of this guide

Strategies for couples

Moving from the romance of a relationship to a care partner changes and can complicate the relationship. There may be feelings of loneliness, grief and loss, not knowing what the future will bring can be stressful. It's important to communicate with each other and discuss what kind of help you may need from each other don't be afraid to ask for help. This is an unsettling diagnosis however it's important to continue doing the many activities that you both enjoy together; you can also find new activities you both enjoy.

There may be different feelings or challenges around your relationship. It is ok to discuss this with the provider caring for your loved one living with dementia. There are also counselors who work with couples on these issues and the changes in relationships.

Strategies for children

It may be hard for children to understand younger-onset dementia. They may be angry, think it is their fault, withdraw or misbehave at school. Consider sharing this diagnosis with the school social worker/counselor, teacher, or nurse, as children may exhibit changes. Everyone processes this diagnosis and disease progression differently, sometimes children benefit from discussing the diagnosis, supporting their needs to express concerns can help.

What can you do?

- Continue to spend time together and find things everyone can enjoy
- Keep yourselves involved in your children's lives
- Be open and honest and talk with the children about what is happening
- Find a support group for your children (there are on-line or in-person support groups)
- If your children are struggling consider talking with a therapist/counselor
- Encourage your children to keep a journal and write down their thoughts
- Consider working with the person living with dementia to create audio or video records of thoughts or messages

CHAPTER 3

Communication



The basics of good communication

- Approach the person from the front
- Always make eye contact
- Identify yourself
- Call person living with dementia by name

Be aware of your communication style

- Use calm tone of voice
- Don't speak too loudly or too softly
- 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 two
- 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. These can prompt the person to perform basic tasks.

Examples of visual cues

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

- 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 may help
- Mirroring a task
  - For example: eating across from each other, helps start the task of eating

How to complete a care task

- Get the person's attention by using their name and making eye contact. If the person is lost in thought, direct their attention to you by gently touching an arm or 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 through the stages of dementia

What to expect in the early stage

- They can make decisions about future care
- They can express 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 straightforward
- 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 use their 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 affect 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, and 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 living with dementia

DON'T		DO
Argue	→	Agree
Reason	→	Divert
Shame	→	Distract
Lecture	→	Reassure
Remember	→	Reminisce
Say "I told you so"	→	Repeat
Say "You can't"	→	Say "Do what you can"
Command or Demand	→	Ask or Model
Condescend	→	Encourage or Praise
Force	→	Reinforce

CHAPTER 4

Understanding Behaviors Related to Dementia



Understanding behaviors
(the way people behave or act)

Dementia affects parts of the brain that control a person's ability to control their own responses. Dementia 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 can be anxious or fearful about 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

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

Completing a task

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

Physical health

- The effects of a medication on the person
- It could be they have impaired vision or hearing
- It could be related to an acute illness (urinary tract infection)
- The effects of another chronic illness (congestive heart failure, diabetes, angina)
- It could be related to dehydration
- It could be related to constipation
- The effects of fatigue
- They may have physical discomfort such as hunger, feeling too hot or too cold

How to manage personality and behavior problems

- Rule out medical causes (especially if there is a quick change in behavior)
- Pay attention to what the person is saying both verbally and non-verbally
- Validate their feelings and try to distract them
- Refocus their attention whenever possible
- Promote a sense of feeling safe and secure and offer reassurance often
- If the person living with dementia is upset, sometimes saying you're sorry may help
- 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



Common behaviors that occur with dementia and what to do

Behavior	Definition	Causes	What to do
Suspicion	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	• Not including person with dementia in conversation or talking about person with dementia like they are not there • Poor vision or hearing • Too much stimulation causing a misunderstanding of what is happening around them	• Don't argue, reason or explain • Offer a simple answer sharing your thoughts • Switch the focus to another activity or ask them to help with something • Duplicate any lost items if the person is often searching for a specific item • Listen to what is upsetting the person and accept their reality, validate this feeling, be reassuring and let them know you care
Aggression	At times a person with dementia is unable to recognize or know how to communicate their needs	• Poor impulse control due to the disease process • Frustration when trying to do something they cannot do anymore • Overstimulation • Discomfort (pain, thirst, hunger) • Response to a caregiver's stress • Feeling scared and someone being in their personal space	• Know what the person likes, dislikes, and their social history • Use calming tactics such as an apology, a smile, offer a snack or to walk with them • If nothing works, leave them alone until they have calmed down
Confusion	A person with dementia may not recognize familiar people, places or things and may forget the purpose of common items "Sundowning" is a group of symptoms that may occur at the end of the day and into the night and causes increased confusion	• A change in living arrangements • A different daily routine • Medical reasons such as an infection (UTI) or low blood sugar • Delirium • Feeling tired • Getting day and night mixed up • Difficulty separating reality from dreams	• Stay calm, do not take it personally • Respond with simple details • Show photos or other reminders • Offer corrections as suggestions ("I think he is your brother Sam.") • Try to keep the same routine day to day
Repetition	When the person with dementia does or says something over and over again, they may be looking for comfort, security, or something familiar	• Memory loss • Not knowing what is happening or a separation from loved one • Not able to express an emotion such as fear, insecurity, and anger	• Focus on the person's feeling and not the behavior, offer reassurance and try to distract the person with a favorite activity • Be calm when answering repeated questions; be patient

Behavior	Definition	Causes	What to do
Feeling Anxious or Agitated	A 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.	• Changes in environment • Travel • Hospitalization • Moving to a new place • Changes in the caregiver • Fear and fatigue from trying to make sense out of a confusing world	• Try to understand what is causing the feeling • Create a calm environment • Provide reassurance • Begin a new activity that might help the person relax such as music, art, taking a walk • Monitor their comfort; could their feelings be related to hunger, thirst, or pain
Inappropriate Sexual Behavior	**Inappropriate sexual behavior (ISB)** may occur in a person with dementia and includes three types of behaviors: **Sexual talk** (obscene, threatening, or abusive language) **Sexual acts** (touching, exposing, public masturbation, fondling) **Implied sexual acts** (public pornography, requesting unnecessary genital care)	**What could cause ISB?** • Need to feel intimacy • Need for comfort • Feeling bored • Uncomfortable • Need to use the toilet • Infection	**Strategies for managing** • Stay calm and be patient. • Gently but firmly tell the person that the behavior is inappropriate. Say "No, stop I don't like that." "Stop that's not right" or just say "Stop." • Distract them and redirect, turn on the TV, music, go for a walk, offer a snack. • Move the person to another location. This takes them away from what may be triggering their behavior. Always be mindful of the persons location. • If nothing else works, startle them a bit by raising your voice and firmly saying "No!" • Identify triggers to prevent ISB. Document the behavior. Keep a behavioral log to assist in figuring out the triggers. • Keep them occupied with different types of engaging activities (fidget activities, stuffed animal, doll). • Boredom can also cause sexual behavior. Keep your older adult happily occupied with different types of engaging • Use adaptive clothing (clothing that may be hard to get on and off). • A discussion with a physician may be helpful to determine the best plan to address ISB.

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

- Look at the person's behavior as communication; I want, I need, I feel.
- We can accept the behavior and provide ways to help the person by offering reassurance or redirection
- We can change our approach through learning new responses
- We can adjust our expectations
- We can remind ourselves the person with dementia is doing the best they can
- 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 understand why you feel that way."*
- Listen
- Label the emotion
- Reframe by asking yourself if the behavior is against you or a response to a situation

What could the 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

Resource: Matters of the Mind and Heart, Beverly L. Moore, RN CS



Catastrophic reaction

Some people with dementia experience what is called a catastrophic reaction. This type of reaction or behavior occurs in a person living with dementia when the situation overwhelms their ability to think or respond appropriately. It is a sudden or extreme 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.

Catastrophic reactions commonly occur at times of change, such as meals, especially dinner, change of caregivers, and bedtime.

How can a catastrophic reaction be prevented?

- To prevent startling them, approach the person from the front, instead of the back or side
- As the care partner, 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 care partner respond to a catastrophic reaction?

- Give the person physical space
- Don't use restraint or force
- Be respectful, and don't talk down to the person living with dementia
- 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 living with dementia may have a health issue and discuss it with their doctor

Wandering

A person living 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 living with dementia may wander and strategies to stop wandering:

- **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
- **Tries or wants to "go to work" or other former obligation**
  What you can do: Use a "Therapeutic Fiblet" (For example, reassure him that today is a day off from work)
- **Is restless or pacing**
  What you can do: Offer exercise or other meaningful activity throughout the day
- **Appears nervous or anxious**
  What you can do: Reduce noise level or other distractions to reduce this feeling.

Possible things that may trigger wandering

- A certain time of day
- Anything new in the person's life (a recent move, new medication)
- The person may be having a 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

If there are concerns about the person living with dementia wandering, consider purchasing location tracking device.



Basic human needs and the language of behavior

People living with dementia 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 a care partner, 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
Inclusion – the need to be part of a larger group	Hovering, clinging, intrusiveness and shadowing	• Involve in a group activity or program • Invite her to stand with you while you are speaking to someone else
Occupation – the need to feel meaningful by exercising abilities and strengths	Boredom, wandering, resisting care, increased agitation	• Empower her to do as much as possible • Engage in familiar tasks like household chores, cooking, cutting coupons or sorting things
Attachment – the need to bond with another person	Fear, paranoia, delusions, exit-seeking	• Have consistent care partners Provide opportunities for socialization to help the person with dementia feel connected to others • Encourage and help with family gatherings.
Comfort – the need to feel tenderness, closeness, warmth and security	Anxiety, fear, panic, anger	• Hugs, hand holding, scratching someone's back, saying, "I love you"
Identity – The need to have one's uniqueness affirmed by others	Depression, withdrawal, isolation, distrust	• Know their life story. Use good communication techniques. Make eye contact. • Use her name often. Introduce her to others telling others something important about her ("Hi, this is Sadie, she has 10 children.")

CHAPTER 5

Safety



General safety concerns for people living with dementia

People living with dementia become increasingly unable to take care of themselves. As a care partner, 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 living with dementia 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 adapted.



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 to identify the food. Such as a bright colored plate on a white place mat
- 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 living with dementia may not smell smoke or may 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 pain
- 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 Such as Q-tips, rocks, potpourri, razor blades, batteries
- 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 **1.800.222.1222** by the telephone
- Keep pet litter boxes away from the person living with dementia

Hearing



- People living with dementia may have normal hearing, but they may lose their ability to correctly understand what they hear
- 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 if the person living with dementia shows signs of being uncomfortable in crowds
- Check hearing aid batteries regularly

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 medications (prescription or over the counter) are kept in the kitchen, store them in a locked cabinet
- Remove all scatter rugs and 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 food
- Insert a drain trap in the kitchen sink to catch anything that is put down the drain
- Consider disconnecting 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
- Use transfer or mobility aids

Living room

- Clear all walk areas 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 person living with advanced 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 hand-held showerhead to make bathing easier

- In the shower, tub, and sink, use a single faucet that mixes 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 can 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, 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 living with dementia is permitted in a garage, shed, or 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 into 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 case 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 child-proof plugs
- Place red tape around floors, radiators, and other heating devices to deter the person living with dementia from standing on or touching a hot surface
- Check all rooms to ensure for good 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. A person living with dementia may choke or suffocate
- Lock or 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, lawn care, driving, snow removal or use of tools

As dementia progresses, these questions will need ongoing evaluation.



Driving safety

Addressing driving concerns is a very sensitive topic and can cause the person living with dementia to be frustrated, anxious and stressed. Taking away access to driving, takes away the feeling of freedom for the person living with dementia. to drive takes away their feeling of freedom. A person's self-identity may be closely connected to driving. Driving provides a sense of independence that is difficult to give up.

How does dementia impact driving?

Concern	Impact on driving
Decreased or poor judgment	Road rage, getting lost, running lights, trouble problem solving (being re-routed because of construction and inability to change driving plan), driving the wrong way, accelerating instead of braking or braking instead of accelerating, challenges to read the gages (warning lights, gas)
Visual spatial relations	Trouble reading signs, how far or how close is the car in front of you or the side of you, challenges with parking and curbs
Slow response time	Braking, stopping for traffic or light changes, lane changes, entering and exiting highways
Confusion to time and place	Getting lost while driving - even to familiar places, forgetting where the car is parked, trouble following directions, not recognizing vehicle in large parking lot

When to have the conversation about driving?

Ideally it is best to have the conversation when the person living with dementia can be involved with planning. It's ok to have the conversation with them over time.

Realistically the conversation doesn't happen for most families until there has been confusion on the road, challenges with parking or direction, getting lost, unexplained damage to vehicles, and challenges pumping gas.



How to have the conversation?

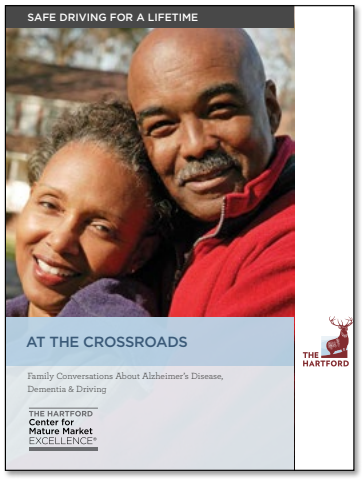
- Relate the need to stop driving as a complication of the disease not that the person did something wrong
- Focus on the disease not the individual as the reason for driving restrictions
- Focus on the impact driving could have on others, i.e. grandchildren, school children, other loved ones
  - *I know you would feel awful if you or someone else got hurt while you were driving*
  - *It's better to be safe than sorry.*
  - *It would be my pleasure to drive you*
- If possible shoulder the blame with another professional (Police Department, Department of Motor Vehicle Department, Physician)
- We want to limit their driving NOT their living, discuss alternate transportation options to ensure they can attend activities that keep them engaged

When the conversation doesn't go well, consider:

- Removing the triggers (car and the keys)
  - Donate the car
  - The car is at the mechanic
  - Someone is borrowing the car
- Disable the car (remove spark plugs, battery) and advise the mechanic what you have done and why
- Provide a fake set of keys

Ensure that all care partners and family involved are informed of plan related to driving concerns and restrictions

A good resource for additional information on driving and dementia is a publication from The Hartford called ***At The Crossroads Family Conversation About Alzheimer's Disease, Dementia and Driving***



Website:
https://s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf

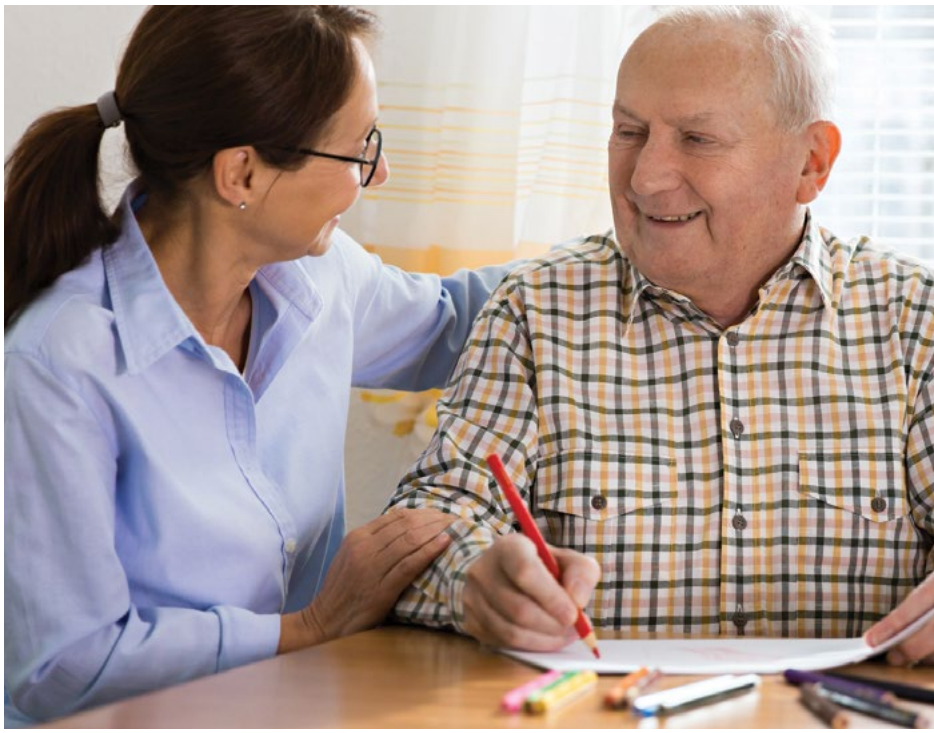
CHAPTER 6

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 adapted to the person's ability. Activities reduce confusion, restlessness, apathy, and psychiatric signs such as delusions, hallucinations and paranoia.



People with dementia may:
Say no to activities
Need activities to remain active
Have a hard time with large groups of people

As the disease progresses:

- Keep in mind what activities the person can do and enjoys
- 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 and safe (housekeeping, office work, yard work)
- Think about the time of day. Does the person do better in the morning or afternoon?

Tips to help make an activity successful for the individual with dementia

- Make it simple – an activity should not need new learning
- Minimal steps to complete
- Make it personal – an activity should be meaningful to the person
- Stress-free – the activity should not be tiring for the person
- Enjoyable – the activity should be focused around personal needs and life

Why encourage someone to participate in activities?

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

Activities can:

- Tap into past interest or skills (cards, house cleaning, arts and crafts, music, and exercise)
- Be related to their past work history or experience
- 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 a 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 the person's strengths, skills and interests are
- 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 living with dementia will change.

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 living with dementia needs a balance of activity and rest.

Morning	❑ 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
Afternoon	❑ Make and eat lunch, read mail, wash dishes ❑ Listen to music, do crossword puzzles, watch TV ❑ Take a walk or visit a friend
Evening	❑ 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 to them

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

50 Activities

to do with an individual who is living with dementia

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 dominoes
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 7

Care Options



Adult Day Centers	Adult Day Centers 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.
Outpatient Rehabilitation	Outpatient rehabilitation or outpatient rehab is a form of rehabilitation therapy which can include: physical therapy, occupational therapy, speech and language therapy, in which patients travel to the facility specifically to participate in rehab treatments. Once the treatment session is completed they return home.

Community care options

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	A skilled nursing facility provides 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, Skilled Nursing Facility) based on individual needs. A resident is able to move throughout the different levels of care within the community.

Residential Care Options

Choosing a care facility

When you visit a community, ask to see the latest report from the state. The report can give you a picture of the facility's services.

- Make an appointment to visit the community
- 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

Family Involvement	❑ Can families communicate with staff about concerns and who in the facility should the family talk to about concerns?
Nursing facility staff	❑ 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?
Programs and Services	❑ 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?
Residents *(person living in the facility)*	❑ Do residents appear comfortable, relaxed and involved in activities? ❑ 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 residents' rooms clean? ❑ Can residents bring personal items with them, such as photos, blanket/sheets, chair?
Meals	❑ 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)?*
Rules	❑ Can family and friends participate in person's 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

How you can partner with rehabilitation

As dementia affects an individual's cognitive functions, physical activity, and self-care tasks; it is beneficial for those with living with dementia to explore treatments provided by physical, occupational and speech therapies to address symptoms, help maintain independence, and improve quality of life. Incorporating therapy interventions early is crucial; however therapy can address all stages of dementia.

Rehabilitation options

Ability Affected	Physical Therapy	Speech Therapy	Occupational Therapy
Memory		■	■
Cognitive Ability		■	■
Motor Skills	■		■
Mood and Behavior	■	■	■
Ability to complete personal care			■
Language & Communication		■	■
Swallowing		■	
Positioning	■		■

Physical therapy can help:

- Maximize mobility, strength and balance to maintain current abilities and slow decline
- Reduce risk of falls
- Identify best ability to increase sense of purpose and decrease frustration with everyday tasks
- Identify approaches to simplify a task including use of familiar tools/ equipment and home modifications
- Identify what will motivate the individual to engage in mobility tasks
- Care partner education to assist with establishing a routine, setting appropriate expectations and providing opportunities for participation in every day tasks

Speech and language therapy can help:

- Obtain baseline measures of cognitive-communication functioning to monitor status over time and utilize patient's strengths to maximize abilities
- Modify the environment to support communication
- Use memory aids or visual cues in the form of pictures or labeling in a meaningful way to support and promote independence. For example, if the person can't remember where the socks are, put a picture of socks on the sock drawer. This is a visual aid to help the person with dementia be successful in completing the task of putting on their socks
- Assess swallowing abilities and provide recommendations for safe swallowing and healthy diet
- Provide care partner support and training

Occupational therapy can help:

- Educate the person living with dementia and their care partners on new ways to meet their ever changing needs
- Assist in minimizing barriers to enhance independence within the home

Emergency planning for the "What Ifs"

It is important to have a plan in case of care partner illness, disability, or death. Who will take care of the person living with dementia if something happens to you?

Things to put in place:

- 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 living with dementia
- Keep a notebook for the person who will taking over the care partner role. In the notebook include:
  - Complete "Introduction to my life tool" (pages 65-67)
  - Emergency phone numbers
  - Present behavior concerns and likely solutions
  - Ways to calm the person living with dementia
  - What help is needed with toileting, feeding, or grooming
  - 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

CHAPTER 8

I’m a Care Partner, now what?



Care partner qualities

Caring for a person living with a dementia can be hard and exhausting work. It has an impact on every aspect of your life.

Care partner attributes

- **Confidence –** that I feel capable for doing this
- **Validation –** that I feel valued for doing this
- **Satisfaction –** that I am doing good and feel good doing this

Care partner emotions

- Guilt might feel like beating yourself up over the decisions you've needed to make regarding care
- Resentment might feel like the frustration you have over the unequal divide of responsibilities
- Anger might feel like the irritation you have about your situation.
- Worry might feel like the uncertainty you feel about what's going on, especially as you look to the future
- Loneliness might feel like the loss of personal relationships
- Grief might feel like the sadness and mourning you're going through, and can sometimes lead to depression
- Defensiveness might feel like you are being challenged for the choices you've made
- Satisfaction might feel like understanding you are doing the best you can, or a sense of pride and purpose in your role
- Empathy might feel like understanding the challenges of the person living with dementia

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

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.

Unintentional consequences of being a care partner

- You may 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 you can do as a care partner:

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

The qualities to be a good dementia care partner

- Sense of humor
- Good eye contact
- Problem solver
- Creative
- Patient
- Interested in learning
- A good communicator
- Relationship builder
- Willing to learn from mistakes

The needs of the person with dementia

- To feel secure and safe
- To feel in control
- To feel loved
- To feel included

How to build a care partner relationship

- Understand the challenges the person living with dementia faces
- Be aware and respect the person's habits and individuality
- Be aware of and respect the person's needs

- Accept what the person is able to do
- Structure the day to help with challenges
- Support the remaining abilities

How to make the relationship positive

- Anticipate needs of the person living with dementia
- Avoid rushing the person
- Use a calm voice – or be silent and wait
- Smile a lot
- Include the person living with dementia in activities
- Shared decision making

How to partner with your healthcare provider

You know the person living with dementia the best. It is important to share everything you know with the members of the healthcare team to keep them 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 the routine of the person living with dementia
- Provide a list of who to call with questions or concerns

Remember: Being a care partner 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 the person living with dementia.



Introduction to my life tool

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

Name	
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	

My childhood	
Memories from school	
My home where I grew up	

My working life	
First job	
Other jobs	
Any memories about work	

Important people in my life	
My spouse's name (if married)	
Names of children (if any)	

My favorite things		
Favorite places		
Favorite holidays		
Favorite hobbies		
Favorite places/vacations		
Favorite activities		
I enjoy (check)	❑ Inside activities	❑ Outside activities
I would rather participate in (check)	❑ Group activities	❑ Individual activities
Favorite Foods		

My life now	
Sleep/ Wake	Time I usually wake up
	Nap times
	Time I go to bed
	My side of the bed
Self-Care Routine	
	Bathing
	Dressing
	Teeth
	Makeup
	Shave
	Take Medications
	Coffee/tea
	Use the bathroom
	Read the paper or watch TV

Bathing preferences (check):			
	❑ Shower	❑ Sponge bath	❑ Tub
	❑ Morning	❑ Afternoon	❑ Evening
	❑ Daily	❑ Every other day	❑ Weekly
Toileting:			
Do you get up during the night?			
How many times a day?			
Favorite hobbies			
What I sleep in (check)	❑ Nude	❑ Underwear	❑ PJ's/Nightgown
Eating:			
	Breakfast	Lunch	Dinner
Foods I like			
Foods I don't like			
I feed myself (check)	❑ Left Handed	❑ Right Handed	
I prefer to drink (check)	❑ Before	❑ With	❑ After
I use assisted devices (check)	❑ Crutches	❑ Cane	
	❑ Walker	❑ Wheelchair	
	❑ Dentures	❑ Hearing aids	❑ Glasses

Additional information you should know about me:



Positive approaches to being a care partner

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 living with dementia are unique and have different needs depending on the disease process, previous education, personality, and interests.

Grief cycle in a dementia care partner

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 care partner 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 care partner 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.

Ways to stop guilt from dementia care

Being a care partner 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."

Care partners 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 care partners 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 care partner 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 their behavior is part of the disease
- Develop and have realistic expectations
- Change your expectations as the disease progresses
- Accept their new behaviors and the loss of social skills

What to do to overcome guilt

- Explore where these feelings are coming from
- Realize that you are not alone in feeling this way
- Find ways to develop positivity and to be more forgiving of yourself

Normal feelings and concerns care partners have that may lead to feelings of guilt

- **How you treated the person before the diagnosis**
  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 care partners 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 care partner and the person living with dementia.
- **You decide the person needs to move into a nursing facility**
  Remind yourself that you have not failed and you are still needed.



Ten real-life strategies for being a dementia care partner

As care partners, 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 dementia is difficult; here is some practical advice:

1. **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 them of this loss, we also remind them of that pain. Many times a person living with dementia will state they want to go home. When we reassure them that they are at home it often leads to an argument. Attempting to redirect them by asking them to tell you about their home. This is a technique that can calm a person with dementia.
2. **Being reasonable, rational and logical may not work.**
   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.
3. **You cannot be a perfect care partner.**
   Just as there is no such thing as a perfect parent, there is no such thing as a perfect care partner. 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 the person living with dementia as well as yourself is essential in the care partner journey.
4. **Therapeutic "fiblets" reduce 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 the person living with dementia thinks they are the volunteer at the day care center? It is okay to tell them 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 them to the doctor. We are raised to speak the truth, therapeutic fiblets may cause an ethical dilemma for some caregivers. If a truthful response causes emotional distress it is better to use a therapeutic fiblet.

5. **Making agreements doesn't work.**
   Typically the person living with dementia has very poor short term memory. If you ask them 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 the person living with dementia 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.**
   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 the person living with dementia 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 the person living with dementia can do.**
   It is often easier to do something for them 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 may make them 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. Knowing the stage of dementia can help manage expectations.

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 the person living with dementia 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 before the dementia diagnosis. 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.



Care partner stress is the emotional and physical strain of being a care partner. Stress can affect your body, your thoughts and feelings, and your behavior.

Ten signs of care partner 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 dementia 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 anymore.
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.

Courtesy of National Alzheimer's Association

If you experience several of these stress symptoms on a regular basis, consult a physician or call the Hartford HealthCare Center for Healthy Aging to help you manage the stress in your life.

Tips for coping/managing stress as a care partner

1. Educate yourself about the disease

- Search out sources of information from your physician, libraries, Internet, Hartford HealthCare Center for Healthy Aging, etc.
- Set realistic expectations for both yourself and the person living with the disease based on your understanding of the disease.

2. Take care of yourself

- To avoid "burn out," plan time for yourself
- Attend to your own health care needs, i.e., exercise, healthy eating, get enough sleep, avoid use of alcohol and pills as aids to reducing stress
- Develop a 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 once did

4. Practice stress-reduction techniques such as:

- Deep breathing, meditation
- Exercise
- Listen to music

5. Ask for help

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

CHAPTER 9

Legal and Financial Concerns



Get started by putting all of your information in place

Official papers available on your state government website

- Living Will
- Durable Power of Attorney for Finances
- Will
- Long-term care insurance policy
- Veteran documents (DD214)
- Healthcare Agent/Representative
- Marriage certificate or divorce decree

Money (financial) documents

- Bank account information and passwords
- Deeds, mortgage papers, ownership statements
- Monthly outstanding bills
- Retirement benefit summaries
- Social Security and pension income
- Stock and bond certificates

Costs you may face

- 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
- Legal documents



Overview of medical, legal, and financial planning documents

Medical Documents	How it is used
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 dementia
Do NOT Resuscitate Form	Instructs health care professionals not to perform CPR in case of the heart stops or breathing stops
Legal/Financial Documents	**How it is used**
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 dementia
Living Trust	Gives a designated person (trustee) the authority to hold and distribute property and funds for the person with dementia
Guardianship/ conservatorship	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). 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. 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.

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

Appendix



Books to help caregivers understand dementia

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 Alzheimer's & 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 and Joan Beloff

Matters of the Mind and the Heart
by Beverly L. Moore

Books to help young children understand dementia

Always My Grandpa: A Story for Children about Alzheimer's Disease
by Linda Scacco, Ph.D. and Nicole E. Wong

Still My Grandma
by Véronique 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 Acceptanc*e
by Kim Gosselin and Tom Dineen

What's Happening to Grampa?
by Maria Shriver

The Graduation of Jake Moon
by Barbara Park

Wilfrid Gordon McDonald Partridge
by Mem Fox, illustrated by Julie Vivas

Children's book on line

Grandma's Cobweb
www.alzheimershope.com/grandmascobwebs/inmemory.php

Books for Younger Onset Dementia

Alzheimer's: A Love Story: One Year in My Husband's Journey
Davidson, Ann Birch Lane, 1997

Alzheimer's from the Inside Out
Taylor, Richard, Ph. D. Health Professions Press, 2007

Before I Forget: Love, Hope, Help and Acceptance in our Fight Against Alzheimer's

Dancing with Dementia: My Story of Living Positively with Dementia
Bryden, Christine, Jessica Kingsley Publishers, 2005

Daughter, Moore Ishbel. Kids Can Press, 1999

Every Single Good Day. Nichols, Max J. Tate, 2005

Ice Cream in the Cupboard:
A True Story of Early Onset Alzheimer's. Moffett, Pat. Garrison-Savanna Pub. 2008

Jan's Story: Love Lost to the Long Goodbye of Alzheimer's
Petersen, Barry. Behler Publications, 2010

Life with Big Al (Early Alzheimer's): A Caregiver's Diary
Seegmiller, Judy. Big Al, 2000

Losing Clive to Younger Onset Dementia
Beaumont, Helen, Jessica Kingsley, 2009

On Pluto: Inside the Mind of Alzheimer's
O'Brien, Greg. Self-published, 2014

Pathways of Hope: Living with Cognitive Changes.
VanRyzin, Christine Baum, Baum, Mary Kay, Milies, Roann Baum, eds. For Memory, Inc., 2011

Seasons of Sun and Rain. (Fiction)
Dorner, Marjorie, Milkweed Edtions, 1999

Show me the Way to Go Home
Rose, Larry. Elder Books, 1996

Singing in the Rain: Weathering the Storm of Dementia with Humor, Love, and Patience Ruppert, Vicky and Henderberg, Ann. Rain Group Press, 2013

Slow Dancing with a Stranger: Lost and Found in the Age of Alzheimer's
Comer, Meryl. Harper, 2015

Still Alice. (Fiction)
Genova, Lisa. Pocket Books, 2007

Surviving Normal
Brewer, Sonja, Aventine Press, 2009

A View From Within: Living with Early Onset Alzheimer's
Raushi, Thaddeus M., Ph. D. Northeastern New York Chapter, Alzheimer's Disease and Related Disorders Association, Inc., 2001

You Forgot, But I still Love You, Reynold:
The Alzheimer Tragedy. Conger, Betty. Self-published, 1999

Young Hope
Mobley, Tracy. Emerald Falcon, 2007

Books for Children/Adolescents

Allie Learns About Alzheimer's Disease:
A Family Story About Love, Patience and Acceptance
Gosselin, Kim, Jay Jo Books, 2001

Always My Grandpa: A Story for Children About Alzheimer's Disease
Scaco, Linda Ph. D. Magination Press, 2006

Alzheimer's Disease (Need to Know Series)
McGuigan, Jim. Heinemann Library, 2004

Alzheimer's Disease: A Forgotten Life
Landau, Elaine. Watts, 2005

A Beautiful Pearl
Whitelaw, Nancy. Whitman, 1991

But, Mama, How Come Grandpa Gets to?
Warren, Carolie. Self-published, 2013

Coping When a Grandparent Has Alzheimer's
Wilkinson, Beth. Rosen, 1996. rev ed

Daughter
Moore, Ishbel, Kids Can Press, 1999

Do You Have a Moon at Your House?
Johnson, Jeanie L. Vantage, Press, 2005

Fading Memories: An Adolescent's Guide to Alzheimer's Disease
American Health Assistance, 1997

Flowers for Grandpa Dan: A Gentle Story to Help Children Understand Alzheimer's Disease McIntyre, Connie. Thumbprint Press, 2005

Forget-Me-Not
Schein, Jonah. Annick, 1988

The Graduation of Jake Moon
Park, Barbara. Simon and Schuster, 2000

Grandfather's Story Cloth
Gardner, Linda and Langford, Sarah. Shen's Books, 2008

Grandma's Soup
Karkowsky, Nancy. Self-published, 1989

Great Uncle Alfred Forgets
Shecter, Ben. Harper Collins, 1996

Jess and the Runaway Grandpa
Woodbury, Mary. Coteau Books, 1999

Let's Talk About When Someone You Love Has Alzheimer's Disease
Weitzman, Elizabeth. Rosen, 1996

Little Mama Forgets
Cruise, Robin. Farrar, Straus and Giroux, 2006

The Magic Tape Recorder: (A Story About Growing Up and Growing Down)
Simard, Joyce. Joyce Simard Pub. And the Czech Alzheimer's Society, 2007

Memory Box
Bahr, Mary. Whitman, 1992

Remember, Grandma?
Langston, Laura. Viking 2004

Remember Me?: Alzheimer's Through the Eyes of a Child
Glass, Sue. Raven Tree Press, 2033

Remember That
Newman, Leslea. Clarion, 1993

Sachiko Means Happiness
Sakai, Kimiko. Children's, 1990

Singing with Momma
Lou Altman, Linda Jacobs. Lee and Low, 2002

Still My Grandma
Van den Abeele, Veronique. Eerdmans Books for Young Readers, 2006

Striped Shirts and Flowered Pants: A Story About Alzheimer's Disease
Schnurbush, Barbara. Magination Press. 2007

Sunsets of Miss Olivia Wiggins
Laminack, Lester L. Peachtree, 1998

What Flowers Remember
Wiersbitzky, Shannon. Self-published 2014

What's Happening to Grandpa?
Shriver, Maria. Little Brown, 2004

What's Wrong with Grandma?: A family 's Experience with Alzheimer's
Shawver, Margaret. Prometheus, 2003

When My Grammy Forgets, I Remember: A Child's Perspective on Dementia
Haaberkown, Toby. Baypoint Publishers, 2015

When Meme Came to Live at My House
Langdon, Mary Janine. Self-published. 1998

Wilfred Gordon McDonald Partridge
Fox, Mem. Kane/Miller, 1995

A Window of Time
Leighton, Audrey O. NADJA Publishing, 1995

Wordsworth Dances the Waltz
Kakugawa, Frances H. Watermark, 2007

A Young Man's Dance
Knowlton, Laurie Lazzaro. Boyds Mills Press, 2006

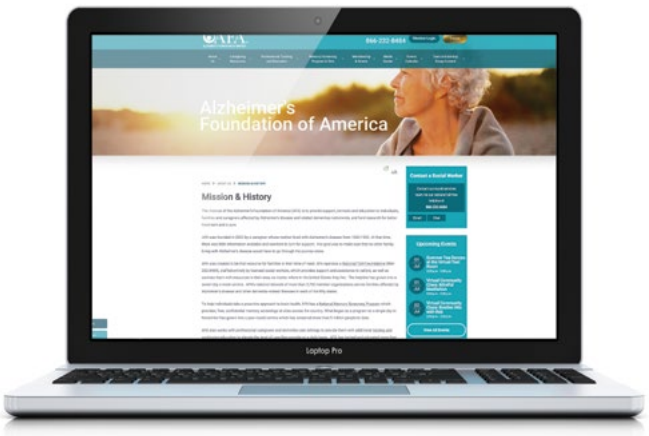
Assistance in your area

Hartford HealthCare
Center for Healthy Aging
1.877.4AGING (1.877.424.4641)

Alzheimer's Association
1.800.272.3900

Area Agency on Aging
1.800.994.9422

Call 211 or visit **211ct.org**



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
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
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

Clinical Trials
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

Lewy Body Association
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
Raises awareness of the Frontontemporal 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
An innovative program that integrates research and educational activities in an effort to improve dementia care.

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Hartford HealthCare

Center for Healthy Aging

Hartford HealthCare Center for Healthy Aging has 12 offices throughout Connecticut.

Contact us at:
1.877.4AGING (1.877.424.4641)
HHCCenterForHealthyAging.org

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