



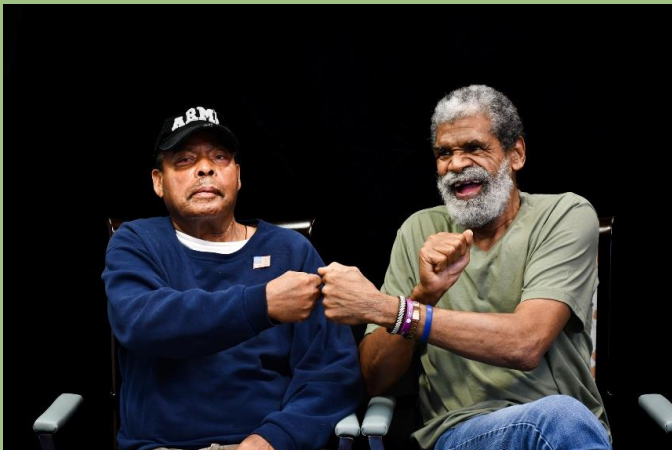
Caregiver Essentials: Tools, Tactics and Takeaways



Learning Objectives

Learn to identify symptoms of Alzheimer's Disease or related dementia (ADRD).

Learn to identify resources to utilize for each stage of the disease.



Every case of dementia looks different – but there are some commonalities.

Learn tips other caregivers have passed along that helped them.

Identify tools that may make caregiving easier.



Riddle: What is It?

- Looks different in every person
- Causes personality changes
- Causes ability changes
- Convinces a person they are well
- Person looks physically well
- Costs billions of dollars
- Is not treatable
- Is thought to be under-diagnosed even with 7.2 million diagnoses now
- May begin 20 years before symptoms start
- Can happen to people at any age



**Alzheimer's
Disease and other
related dementias.**



Defining Dementia



There are over 400 different types of dementia.

Dementia is an umbrella term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life.

Alzheimer's Disease is the most common type of dementia. It is associated with protein plaques and tangles. (60-80% of all types of dementia)

Vascular Dementia is caused when blood vessels in the brain are damaged or injured. (5-10%)

Frontotemporal Degeneration – nerve cells in the front and temporal lobes of the brain die affecting personality more than memory. (3% are under 65, 10% are older)

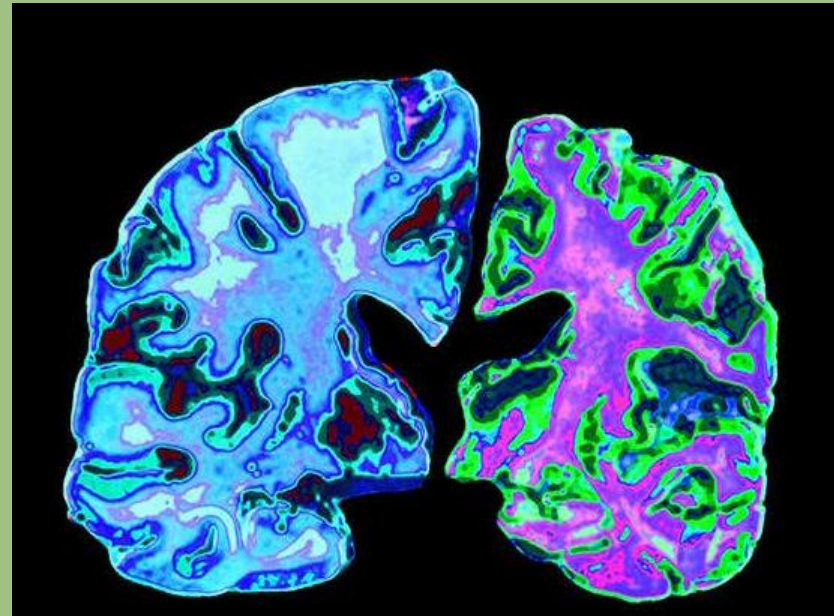
Lewy Body Disease – clumps of Lewy Body protein develop in the neurons in the brain affecting person's thinking, movement, behavior and mood. (5% of population)

Mixed dementia – when someone shows brain changes of more than one type of dementia. (More than 50% of people with Alzheimer's have mixed dementia.)



Defining Alzheimer's Disease

- Alzheimer's Disease is the most common form of dementia.
- Caused by the development of plaques and tangles which cause irreversible and damaging changes to the brain. The changes are progressive.
- The changes in the brain include inflammation and decreased ability of the brain to use glucose.
- The disease causes the brain to decrease in size.



<https://www.newscientist.com/definition/alzheimers-disease/>

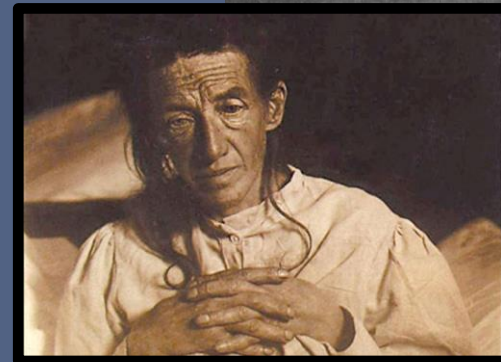
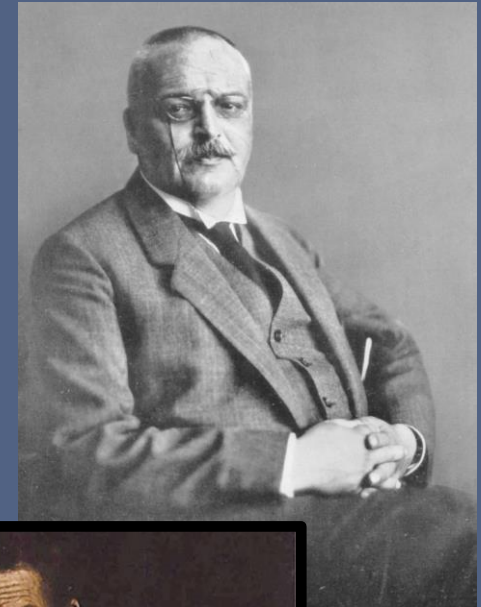
<https://www.alz.org/getmedia/ef8f48f9-ad36-48ea-87f9-b74034635c1e/alzheimers-facts-and-figures.pdf>



Defining Alzheimer's Disease

November 26, 1901 – Auguste D, a 51-year-old female was admitted to the Frankfurt Asylum in Germany and put under the care of Dr. Alois Alzheimer, a biology psychiatrist.

1995 – Dr. Alois Alzheimer's care notes were found, fully intact, with brain tissue taken during Auguste D's autopsy and a well-preserved photograph of her. The finding of his notes fully confirmed Auguste D as the first documented Alzheimer's patient.



[Click here for Alzheimer's Milestones](#)



Activities of Daily Living

Instrumental Activities of Daily Living (IADL)

- Housekeeping – maintaining a clean & organized living environment
- Phone Use – being able to use a phone to call for emergency services
- Food prep – planning, cooking & serving meals
- Shopping – locating items to purchase and making change or paying for those items
- Transportation - driving or managing transportation systems
- Laundry – using washing machine and dryer, sorting clothing
- Money Management – paying bills and managing a budget
- Medication Management – obtaining, sorting and taking medication as prescribed

Activities of Daily Living (ADL)

- Feeding – being able to feed oneself
- Dressing – select appropriate clothes and put them on
- Bathing – ability to bathe and groom oneself, maintaining dental hygiene, nail and hair care
- Toileting – the ability to get to and from the toilet, use it appropriately and clean oneself
- Transferring – being able to move from one position to another and walk independently
- Continence – the ability to control bladder and bowel function





Let's Talk about Stages



<https://www.belightcare.com/post/understanding-the-stages-of-dementia>



What are the commonly known stages?

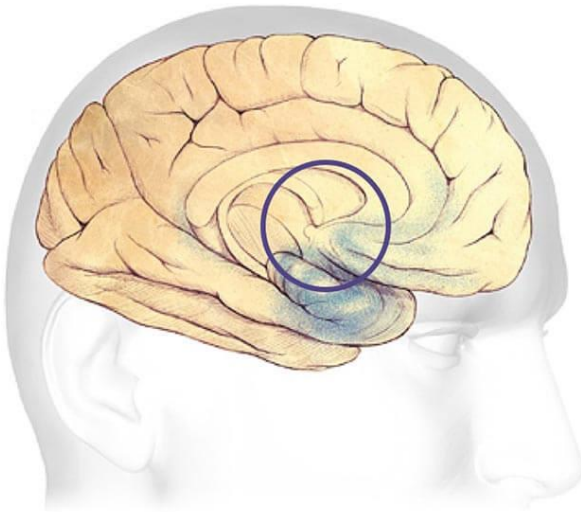
Mild/ Early Stage (Clinical Stage 0 to 3)– a person may function independently. They may still drive, work and participate in social activities. They may feel like they are having memory lapses such as forgetting familiar words or the location of everyday objects. Close family and friends may notice changes and a doctor may be able to identify symptoms using diagnostic tools. **IADL Changes:** Keeping house poorly, struggling to use the phone, remote, computer, difficulty making shopping change, getting meds confused or refusing to take them anymore. **No ADL changes.**

Moderate/ Middle Stage (Clinical Stage 4 & 5) – As the disease progresses, a person will require help with care. They may confuse words, get frustrated or angry, or act in unexpected ways. They may struggle to express thoughts and perform routine tasks without help. Tasks will need to be simplified and then the person coached through steps. Caregivers will need respite care. **IADL Changes:** Housekeeping, phone or electronic use, unable to shop, unable to manage medications, unable to do laundry, skip steps in recipes, unable to react appropriately to unexpected stimuli. **ADL changes:** needs help dressing, bathing, toileting. Incontinence starts. Mobility aides may be needed.

Severe/ End Stage (Clinical Stage 6) – Symptoms are severe. A person loses the ability to respond to the environment, carry on conversations and control movement. Significant personality changes may take place and the person will need significant help with care. The person may not be able to initiate a conversation but can benefit from listening to music and gentle touch. **All IADLs need assistance. Most ADLs need help, and person becomes fully dependent on others.**



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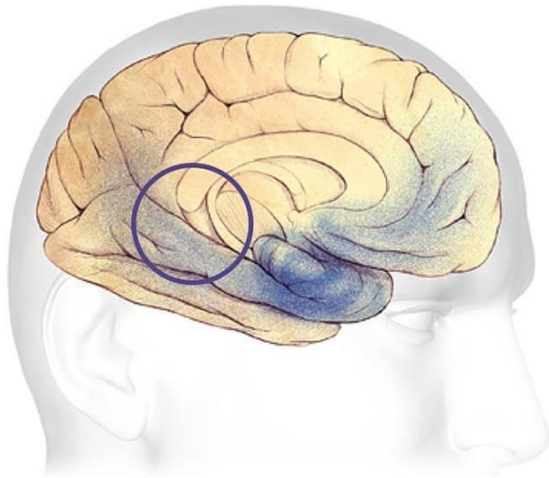
Learning and
Memory



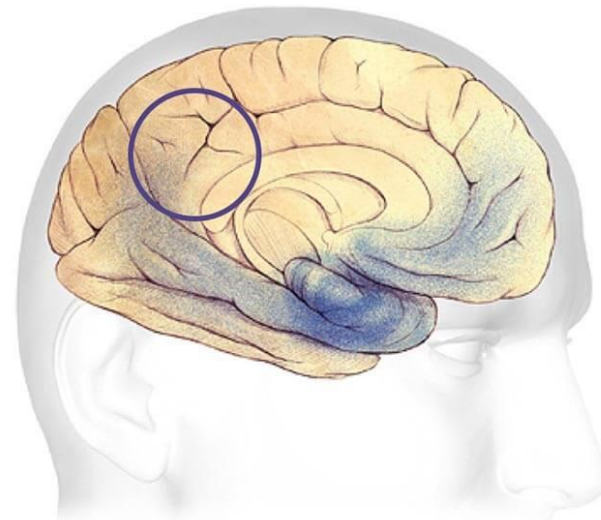
Thinking and
Planning



Moderate/ Middle Stage (Clinical Stage 4 & 5) – This is the longest stage and can last many years. As the disease progresses, a person will require help with care. They may confuse words, get frustrated or angry, or act in unexpected ways. They may struggle to express thoughts and perform routine tasks without help. Tasks will need to be simplified and then the person coached through steps. Caregivers will need respite care. **IADL Changes:** Housekeeping, phone or electronic use, unable to shop, unable to manage medications, unable to do laundry, skip steps in recipes, unable to react appropriately to unexpected stimuli. **ADL changes:** needs help dressing, bathing, toileting. **Incontinence starts. Mobility aides may be needed.**



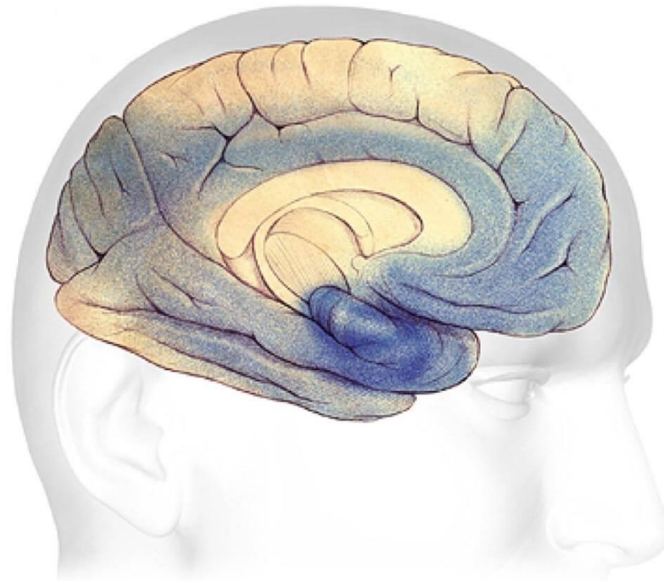
Speaking and Understanding
Speech



Sense of where your body is in
relation to objects around you.

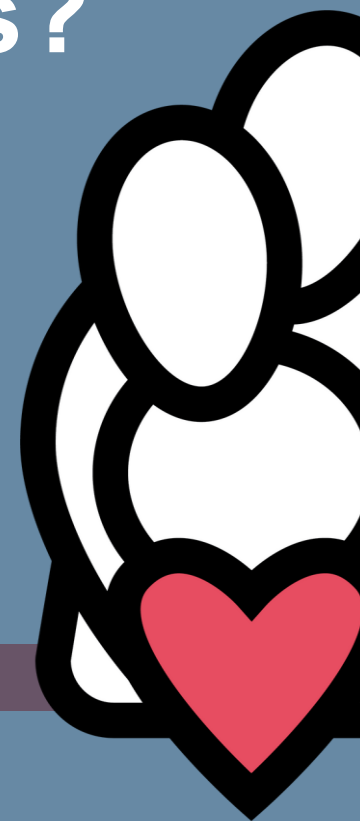


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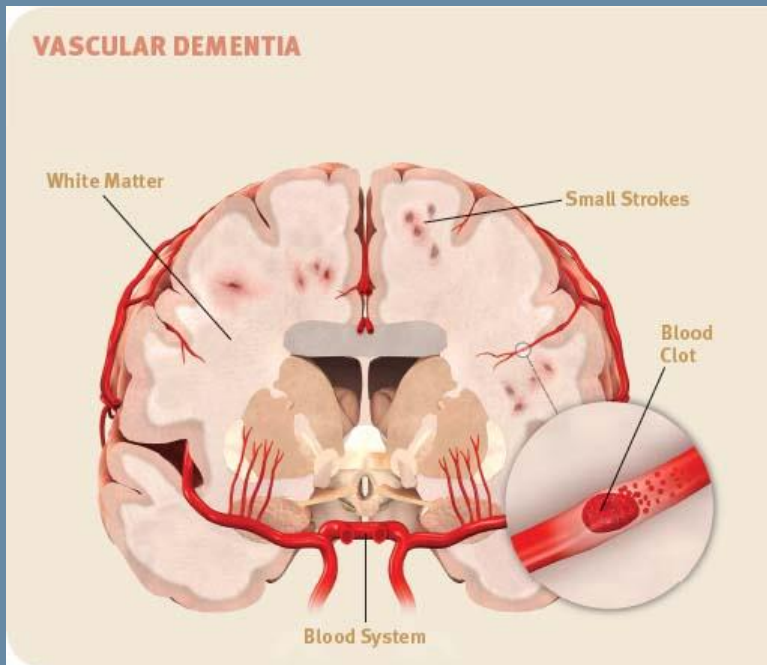


What About Other Dementias?



Vascular Dementia

5-10% of cases are vascular alone. Most common mixed pathology with Alzheimer's Disease.



Symptoms vary due to the cause. Strokes cause a person to be confused, disoriented and have trouble speaking.

Small strokes cause impaired judgement, sudden bursts of laughter or tears, lack of focus, difficulty finding words, absentmindedness, tremors, muscle weakness and balance problems. Memory loss is common.

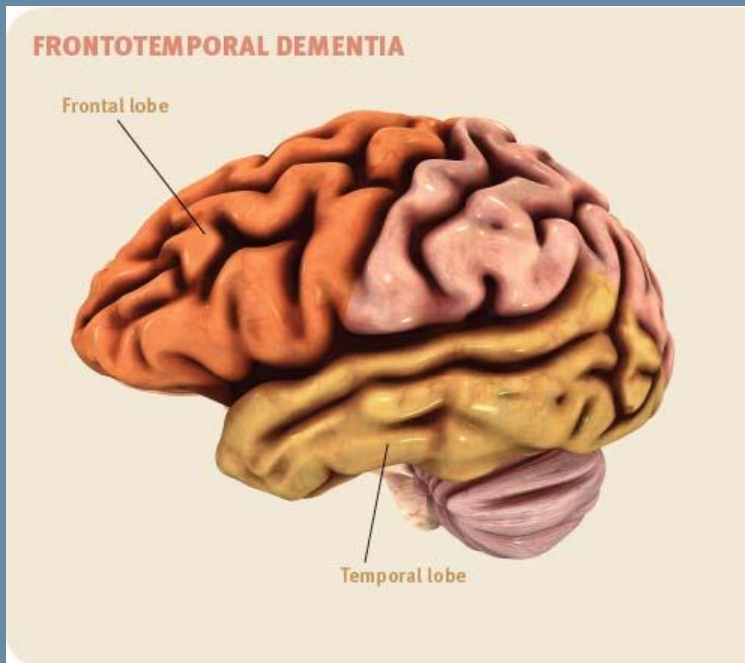
Stages similar to Alzheimer's disease but don't always progress in linear progression or a set timeline.

May be mixed with other dementia types.



Frontotemporal Dementia

60% of cases are people age 45 to 60. About 3% of dementia cases over age 65 are attributed to FTD.



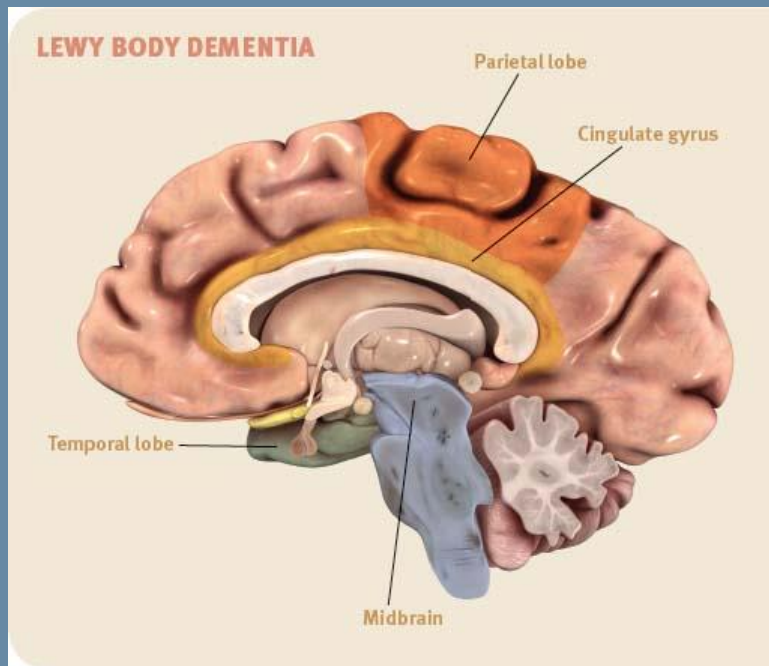
Umbrella term for a group of conditions (behavioral-variant FTD, primary progressive aphasia). Two different proteins called tau and TDP-43 attack the brain's frontal and temporal lobes (sections behind the forehead and ears) that affect behavior, language, motor function and causes progressive loss of nerve cells.

Most notable symptom is change in behavior – aggressive behavior, inappropriate language – or trouble forming sentences or speaking coherently. Memory loss is not a symptom until disease progresses.



Lewy Body Dementia

About 5% of older PLWD show evidence of LBD alone. Most people have brain changes of Alzheimer's disease.

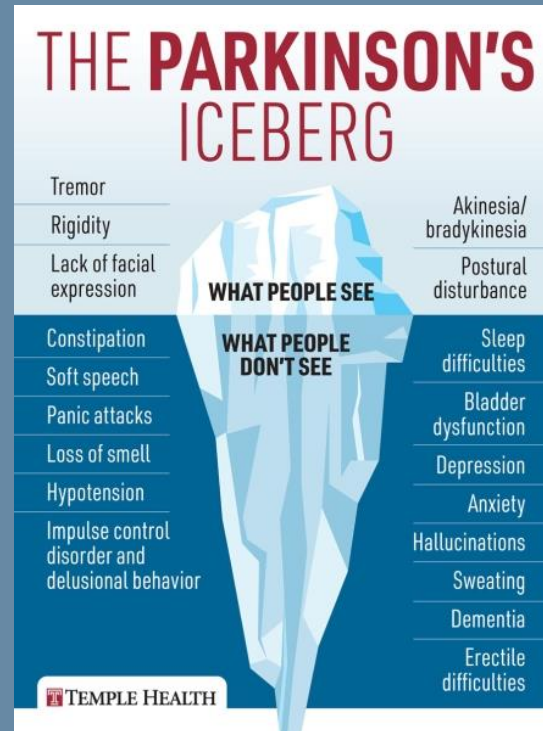
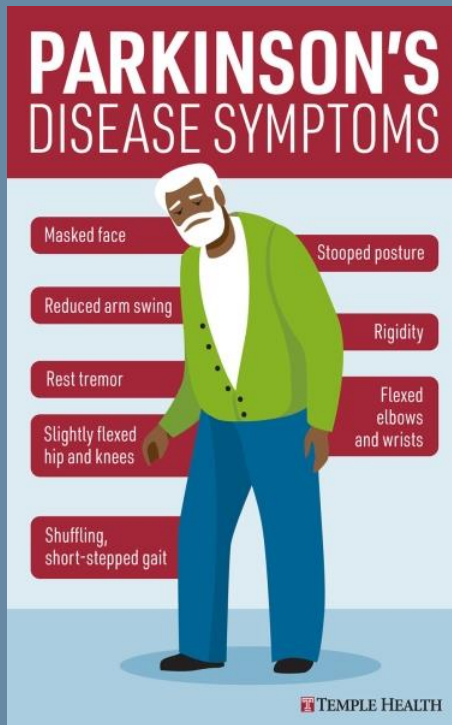


Occurs when protein deposits called Lewy Bodies accumulate in nerve cells in the areas of the brain responsible for memory, motor control, and thinking.

As the disease progresses and spreads, symptoms of Parkinsonian symptoms may appear. Visual hallucinations are common. Moods and awareness may fluctuate. Sleep disturbances are common and includes acting out dreams at night.



Parkinson's Disease



Parkinson's Disease is a movement disorder that could develop into Parkinson's Disease Dementia.

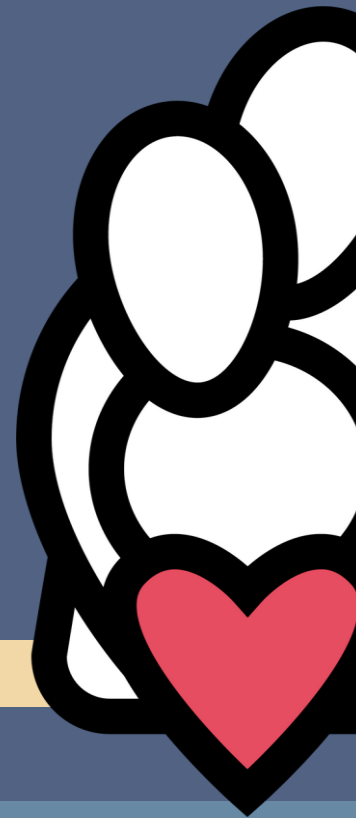
3.6% of dementia cases were due to Parkinson's Disease and 24.5% of PD developed dementia.

It's important to know there is more to Parkinson's Disease than meets the eye.





Staging Resources



First...



Making a plan can eliminate fear
and allow us to enjoy the journey.

Mild/Early (Clinical Stages 0-3)

- ✓ Identify surrogate decision-maker, review their role, include in discussions.
- ✓ Complete advanced directives & utilize **elder law attorney** for legal documents.
- ✓ Discuss future care preferences such as hospitalization, life sustaining measures, etc. and clarify as needed.
- ✓ Access support and resources (**adult day care, transportation, house keeping help**).
- ✓ Discuss safety concerns (**driving cessation, gun safety and medication management**).
- ✓ Discuss wandering safety (35-60% of people living with dementia wander at least once.) **Doorbell cameras, GPS trackers, neighborhood watch** can help.



Early Stages Tips and Tools

Tips

Set up resources early! (No one ever came off of a waiting list that they weren't on to begin with.)

Establish and maintain a routine.

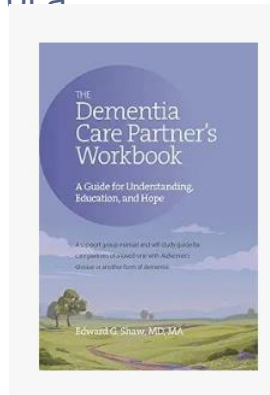
Add yourself to your "to do" list.

Don't argue.

Simplify everything – communication, tasks, meals, TV shows

Remove clutter

Re-home or surrender weapons.



Tools

BeLightCare on Facebook and Instagram

The Dementia Care Partner's Workbook

by Dr. Edward G Shaw (available on

<https://a.co/d/12UiXii>
Amazon)

Coloring Books and Pencils (available at Dollar Tree)

Educate Yourself:

- Powerful Tools for Caregivers
- The Empowered Caregiver Series
- Caregiver Education Seminars

Senior Services Caregiver Resources Webpage: <https://seniorservicesinc.org/caregiver-resources/>



Second



Making a plan can eliminate fear
and allow us to enjoy the journey.

GUIDE

Guiding an Improved Dementia Experience

Must have original Medicare.

More info:

<https://www.cms.gov/priorities/innovation/innovation-models/guide>

Moderate/ Middle-Stage (Clinical Stage 4-5):

- ✓ Access caregiver support and educational materials (**caregiver support group, respite**).
- ✓ Address common dementia-related behaviors (apathy, depression, agitation, irritation, paranoia, hallucinations, wandering, sundowning). **Art & music therapy** may help.
- ✓ Explore options for daily activities or living arrangements (**adult day care, home delivered meals, in home bathing support, assisted living**).
- ✓ Regularly utilize **respite**
- ✓ Discuss signs the disease is progressing (infections, hospitalizations, increased care needs, eating or swallowing difficulties).
- ✓ Address safety concerns not previously reviewed.



Middle Stages Tips

Tips

Always have an answer to “let me know if you need anything”!

Maintain routine – limit naps!

Join a support group.

Lock up poisons and cleaning supplies

Utilize **Respite** options

Set up cameras.

Consider Adult Day Care or Respite for All



Middle Stages Tools



Car Handle

<https://a.co/d/8Da5Ilv>



Door alarm w/ app

<https://a.co/d/22XEIAa>



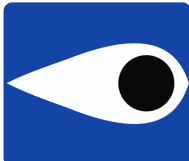
Side snap robe

<https://a.co/d/ftj1JOd>



GPS Tracker

**NEIGHBORHOOD
WATCH**



WE LOOK OUT FOR EACH OTHER

<https://a.co/d/OZxWF19>



Fidget Book

<https://a.co/d/2oCi5YR>



Simplified Clock

<https://a.co/d/5iqMEZV>



Bed/Room Alarm

<https://a.co/d/8s18d3U>



Final...

Making a plan can eliminate fear
and allow us to enjoy the journey.



End Stage (Clinical Stage 6):

- ✓ Address concerns about swallowing, eating and weight loss.
- ✓ If not already done so, discuss alternative living arrangements (**assisted living or skilled care, hospital bed at home, lift chair**).
- ✓ Explore **Hospice** benefits and options.
- ✓ Review focus of care (comfort vs life-prolongation).
- ✓ Focus on personal needs, comfort, symptom and pain management.



Final Stage Tips and Tools

Tips

Give yourself time to process emotions.

Give yourself permission to skip chores.

Utilize Hospice support and services.

Use music and gentle touch.

Turn and move loved one often.

Don't force water or food.

Focus on Quality of Life.



Tools

Hospital Bed

Bed Pad & Mattress Protector

No Rinse Bath Products

Lotion

Music





Thank you!

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