

How To Help People Live Well With Dementia!

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Dementia Quiz

1. Which is the most prevalent type of progressive dementia?
 - A. Vascular Dementia
 - B. Alzheimer's Dementia
 - C. Fronto-temporal Dementia
 - D. Dementia with Lewy Bodies

2. How is Alzheimer's Disease diagnosed?
 - A. Mental Status Tests
 - B. Blood Tests
 - C. Neurologic Tests
 - D. All of the above

3. Which of these is the strongest risk factor for developing Alzheimer's?
 - A. Heredity
 - B. Age
 - C. Exposure to toxins
 - D. None of the above



Dementia Quiz

4. Because there is no medical cure for Alzheimer's Disease, emphasis is placed on delaying the onset of severe symptoms. Which of these strategies help?

- A. Exercise
- B. Hobbies
- C. Good nutrition
- D. All of the above

5. If you care for a family member with dementia, which of these measures will help stabilize the person mentally?

- A. Move to a small apartment
- B. Correct "bad" behavior gently
- C. Establish a regular routine
- D. Repaint or buy new furniture



Dementia Quiz

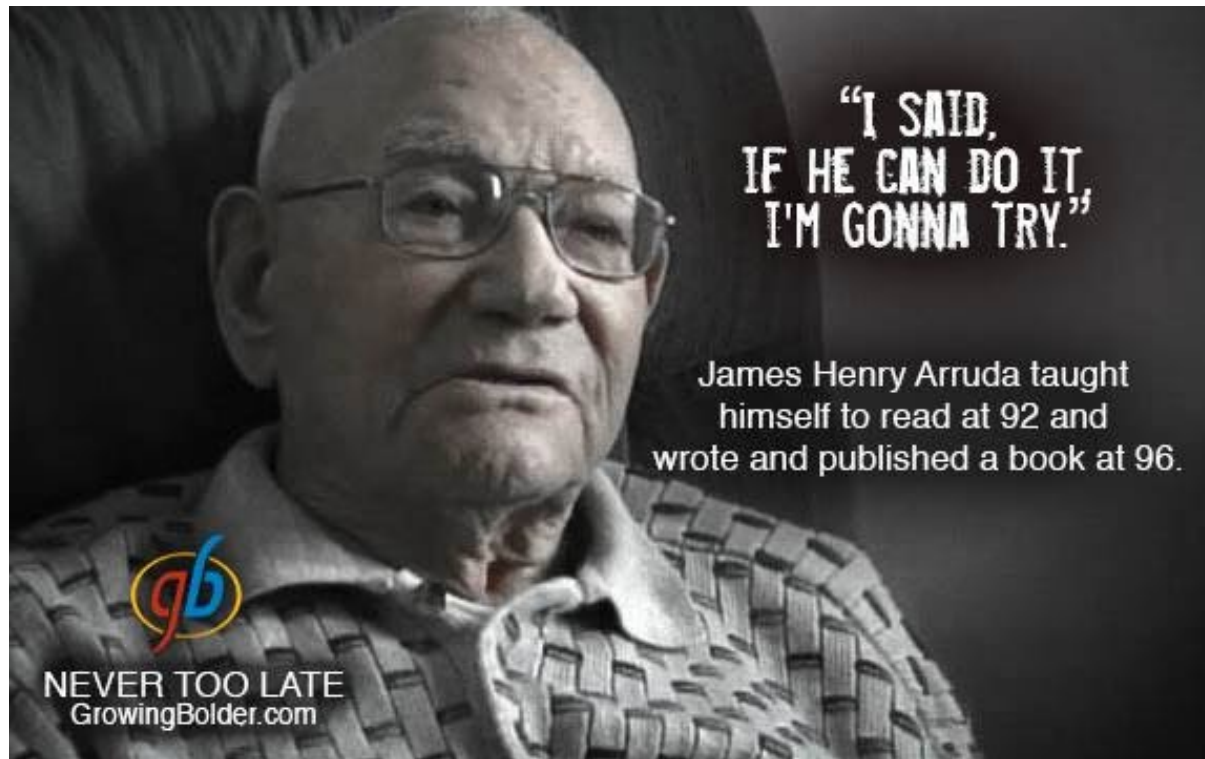
6. There is a new blood test that will tell you if you definitively have Alzheimer's Disease.

- A. True
- B. False

5. The new Medications available for Alzheimer's Disease are appropriate for which stage

- A. Early Stages
- B. Middle Stages
- C. Late Stages
- D. All of the Above

Aging...



*Society has pre-conceived
notions about aging and what
is possible...*

*People also have similar pre-
conceived notions about
dementia!*



Quality of Life and Wellbeing

- Quality of Life is very subjective
- Its all about Compensation and Adaptation!!!
- This program is all about Quality of Life and Wellbeing and living well with dementia because,

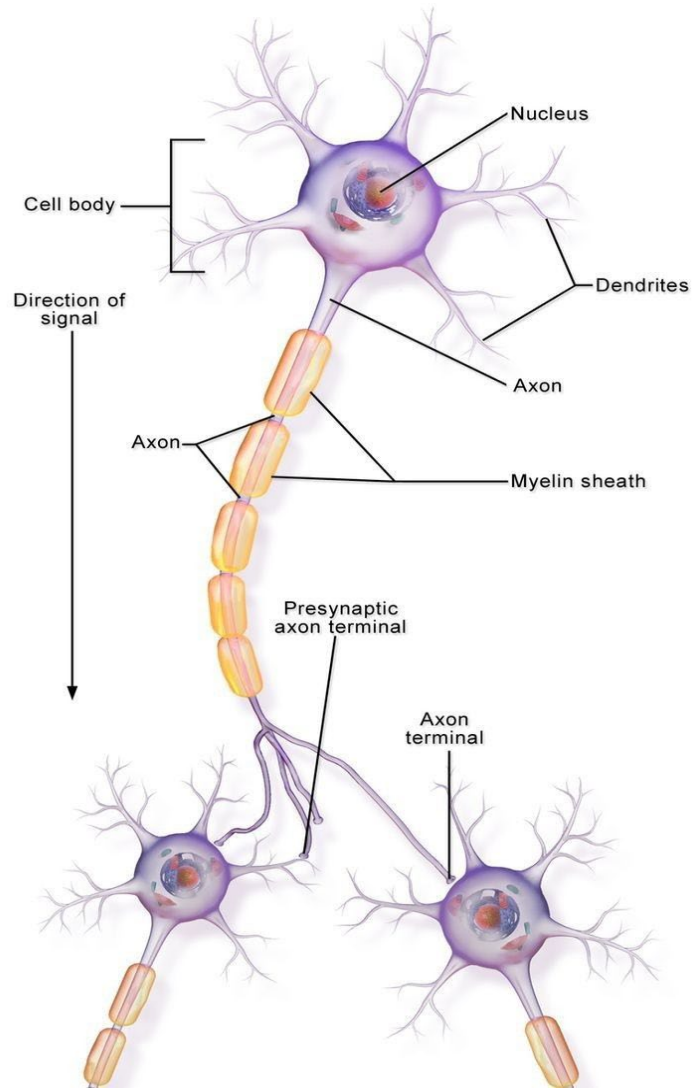
*You can't change the fact that you have dementia,
but...*

You CAN change the way you choose to live with it!

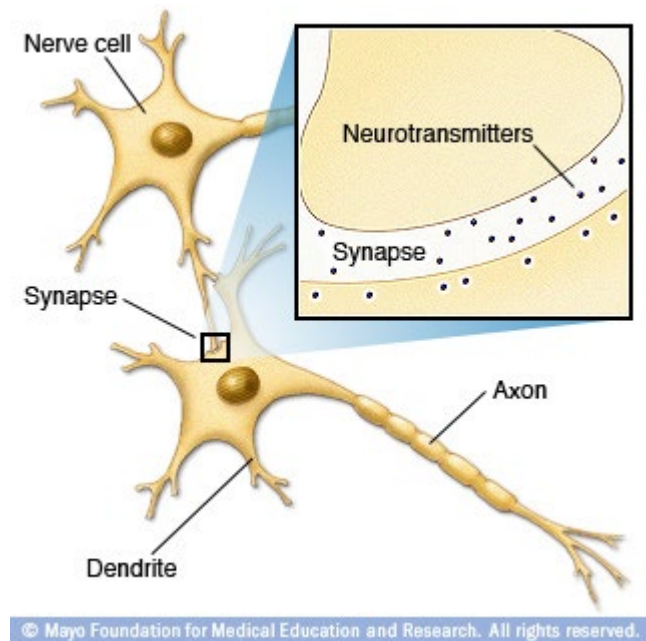
Living Well With Dementia

- How The Brain Communicates
- Types of Dementia
- Understanding the Person with Dementia
 - Cognitive and Perceptual Changes
 - Communication and Understanding Reactive Behaviors
- Quality of Life and Wellbeing during Dementia
 - The Lived Experiences of People With Dementia
 - Modifications to Maintain Independence
 - The Importance of Maintaining Personhood
 - Positive Emotions
 - Living in the Moment

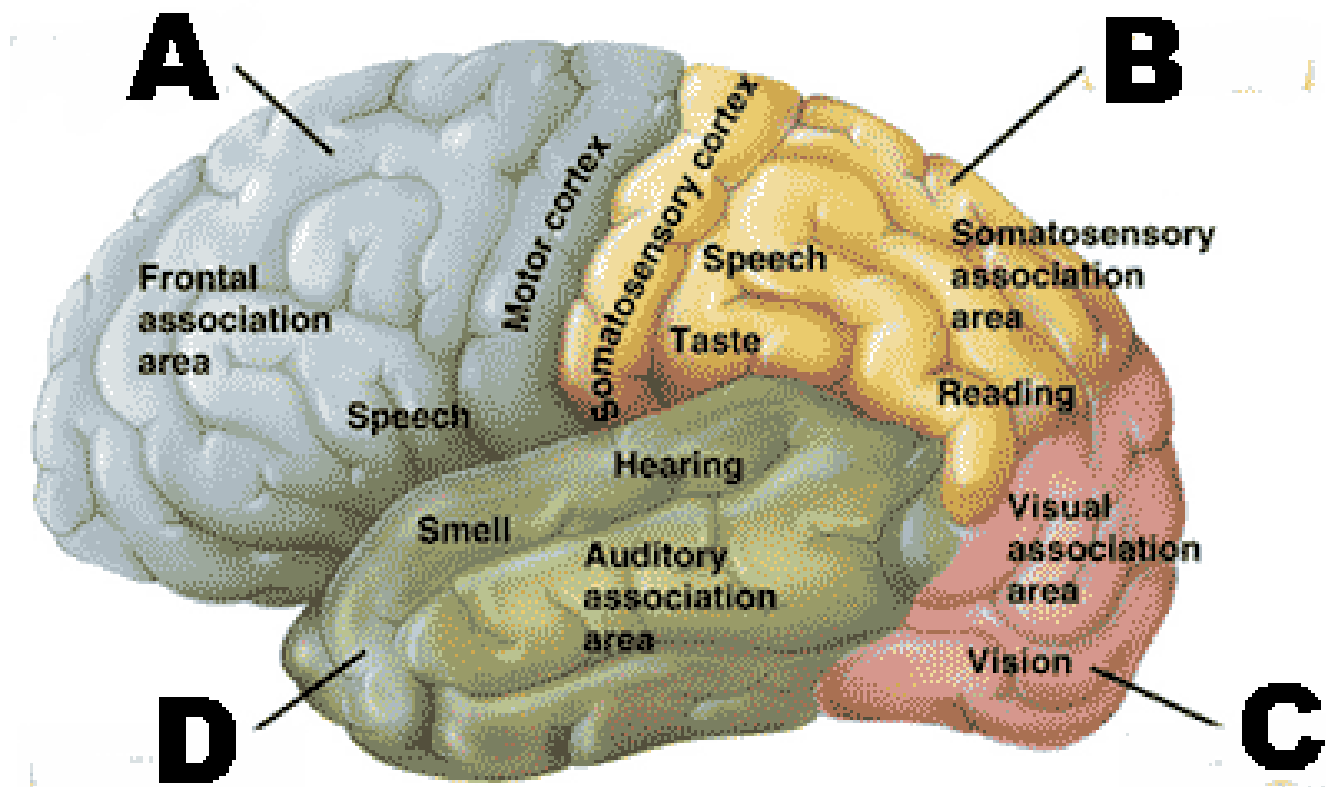
Nerve Cell Connections: Synapses



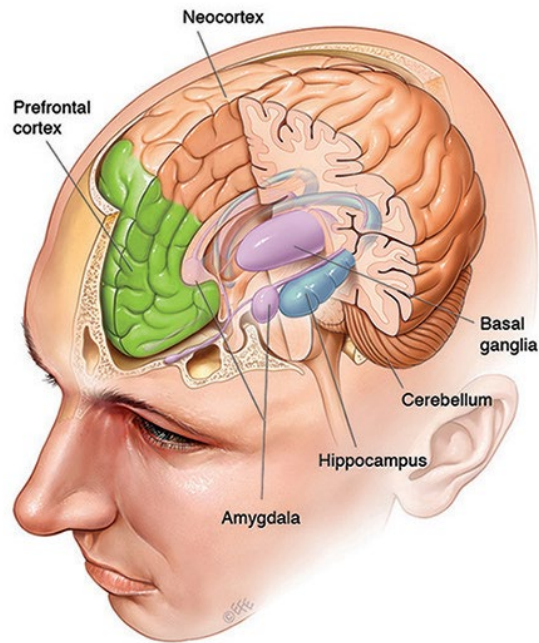
The places where neurons connect and communicate with each other are called **Synapses**



How Your Brain Is Organized



Areas Affected by Normal Aging of the Brain...

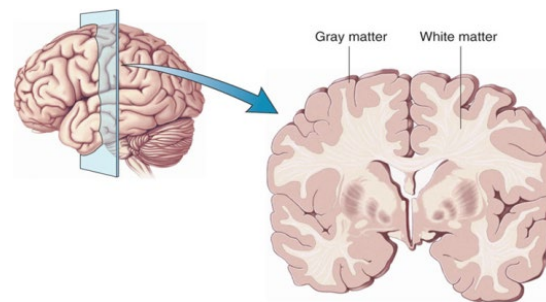
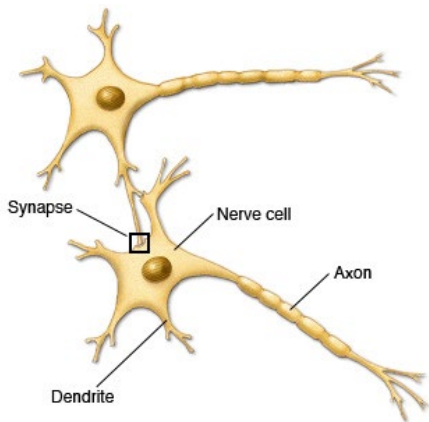


Prefrontal Cortex

- Executive Function Declines
- Harder to Focus Attention
- Harder to Multitask

Hippocampus

- Memory
- Loss of Receptors Makes it Harder to Concentrate



Axons

Processing Speed Slows

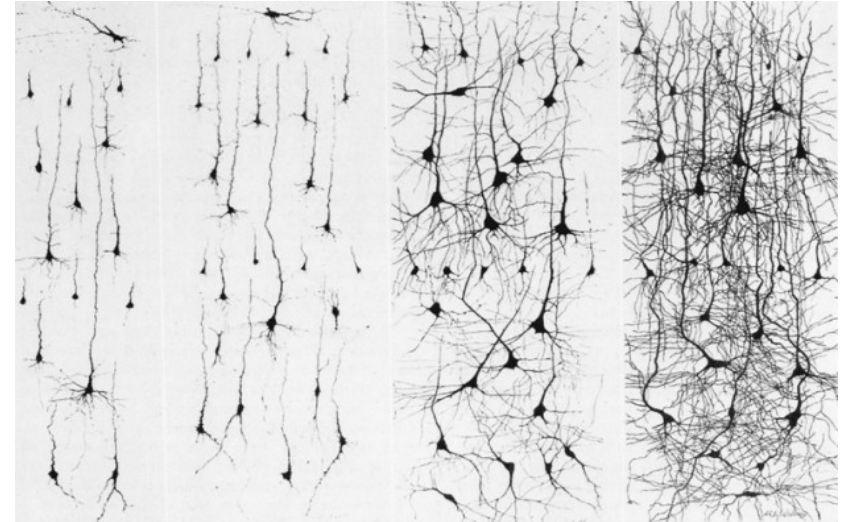
© Mayo Foundation for Medical Education and Research. All rights reserved.

Neuroplasticity

Neuroplasticity refers to our brain's ability to change in response to experience.

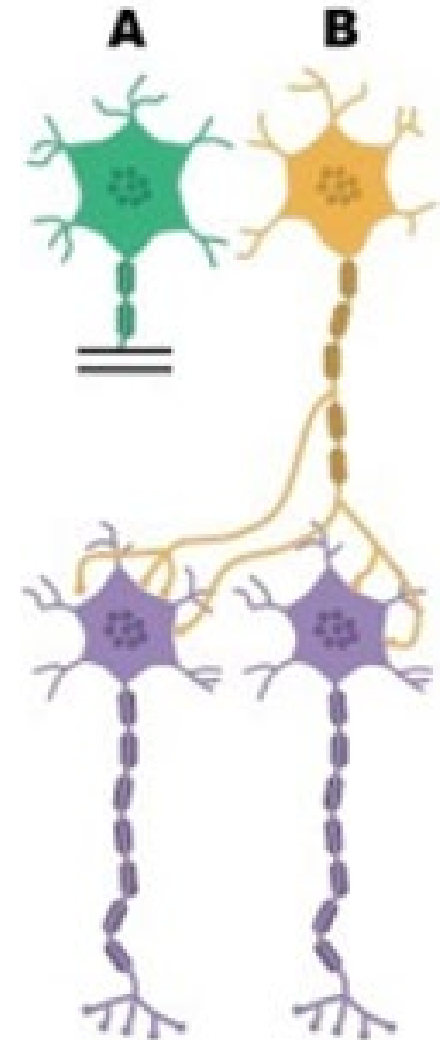
The brain has the capability to form and reorganize synaptic connections, especially in response to learning, experience or following injury.

In this way, alternate circuits or pathways can be established for lost or injured neurons.



“CELLS THAT FIRE TOGETHER, WIRE TOGETHER”

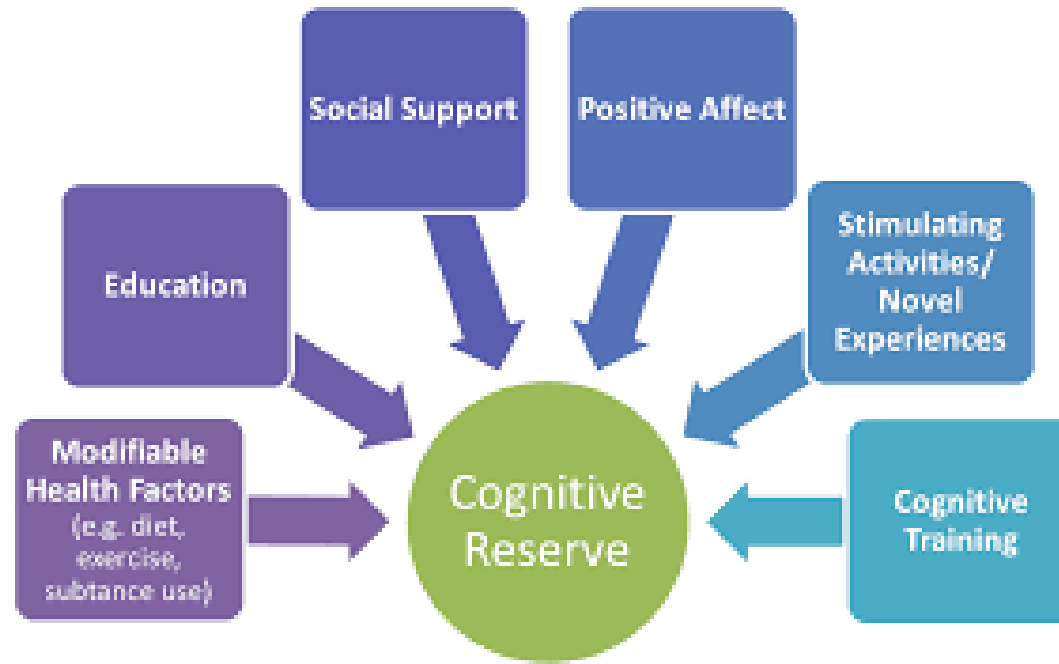
New Axon and Dendrite extensions
allow existing neurons to form new
connections



Collateral sprouting of
neuron B after damage
to axon of neuron A

Cognitive Reserve

How much you have used your brain
and built up connections throughout your lifetime



- Results from a lifetime collection of cognitive stimulating experiences
- Research suggests increased cognitive reserve results in decreased expression of pathologies as dementia due to neuronal compensation
- Research also finds that you can still add cognitive reserve, although at a lessor rate, into the early and middle stages of dementia

Dementia

Need Assistance To Navigate The Day

1. Memory loss especially short term memory, disrupting daily life
2. Challenges in planning and problem solving
3. Difficulty completing familiar tasks at home, work or leisure
4. Confusion with time or place
5. Trouble with visual and spatial relationships
6. Problem with words in speaking or writing
7. Misplacing things and unable to retrace your steps
8. Poor Judgment
9. Withdrawal from work or social activities
10. Unexplained changes in mood or personality *From: Alzheimers Association*

My Number One Question

What is the difference between
Alzheimer's Disease
And
Dementia?

Over 100 Different Types/ Causes of Dementia

Alzheimer's Disease
Vascular Dementia
Dementia with Lewy Bodies (DLB)
Frontotemporal Dementia (FTD)
Mixed Dementia
Parkinson's Disease Dementia
Creutzfeldt-Jakob Disease
Huntington's Disease
Wernicke-Korsakoff Syndrome
Normal Pressure Hydrocephalus (NPH)
Posterior Cortical Atrophy
Primary Progressive Aphasia
Semantic Dementia
Progressive Supranuclear Palsy
Corticobasal Degeneration
Chronic Traumatic Encephalopathy (CTE)
HIV-Associated Dementia
Neurosyphilis
Substance-Induced Dementia
Dementia Pugilistica
Binswanger's Disease
CADASIL (Cerebral Autosomal Dominant Arteriopathy)
Familial Alzheimer's Disease
Down Syndrome-Associated Alzheimer's Disease
Rapidly Progressive Dementia
Transient Global Amnesia
Transient Ischemic Attack (TIA)-Related Dementia
Limbic-Predominant Age-Related TDP-43 Encephalopathy (LATE)
Argyophilic Grain Disease
Neuridegeneration /Iron Acclumulation
Multiple System Atrophy
Spinocerebellar Ataxia
Wilson's Disease

Mitochondrial Encephalomyopathy
Neuroacanthocytosis
Prion Diseases
Familial British Dementia
Familial Danish Dementia
Gerstmann-Sträussler-Scheinker Syndrome
Fatal Familial Insomnia
Kuru
Alpers' Disease
Alexander Disease
Canavan Disease
Krabbe Disease
Metachromatic Leukodystrophy
Pelizaeus-Merzbacher Disease
Zellweger Syndrome
Refsum Disease
Adrenoleukodystrophy
Cerebrotendinous Xanthomatosis
Niemann-Pick Disease
Tay-Sachs Disease
Sandhoff Disease
Gaucher Disease
Fabry Disease
Mucopolysaccharidoses
Sialidosis
Galactosialidosis
Schindler Disease
Farber Disease
GM1 Gangliosidosis
GM2 Gangliosidosis
Fucosidosis
Mannosidosis
Aspartylglucosaminuria
Sjögren-Larsson Syndrome
Ceroid Lipofuscinosis
Infantile Neuroaxonal Dystrophy

Juvenile Neuronal Ceroid Lipofuscinosis
Adult Neuronal Ceroid Lipofuscinosis
Kufs Disease
Batten Disease
Lafora Disease
Unverricht-Lundborg Disease
Myoclonic Epilepsy with Ragged Red Fibers (MERRF)
Leigh Syndrome
MELAS Syndrome (Mitochondrial Encephalomyopathy, Lactic Acidosis, and Stroke-like episodes)
Kearns-Sayre Syndrome
Pearson Syndrome
Barth Syndrome
Alpers-Huttenlocher Syndrome
Leukoencephalopathy with Brainstem and Spinal Cord Involvement and Lactate Elevation (LBSL)
Vanishing White Matter Disease
Adult Polyglucosan Body Disease
Hereditary Diffuse Leukoencephalopathy with Spheroids
Cerebral Amyloid Angiopathy
Amyotrophic Lateral Sclerosis (ALS)-Associated Dementia
Primary Lateral Sclerosis
Progressive Bulbar Palsy
Spinal Muscular Atrophy
Kennedy's Disease
Charcot-Marie-Tooth Disease
Hereditary Spastic Paraplegia
Friedreich's Ataxia
Ataxia-Telangiectasia
Machado-Joseph Disease
Spinocerebellar Ataxia Type 1
Spinocerebellar Ataxia Type 2
Spinocerebellar Ataxia Type 3

Types of Dementia

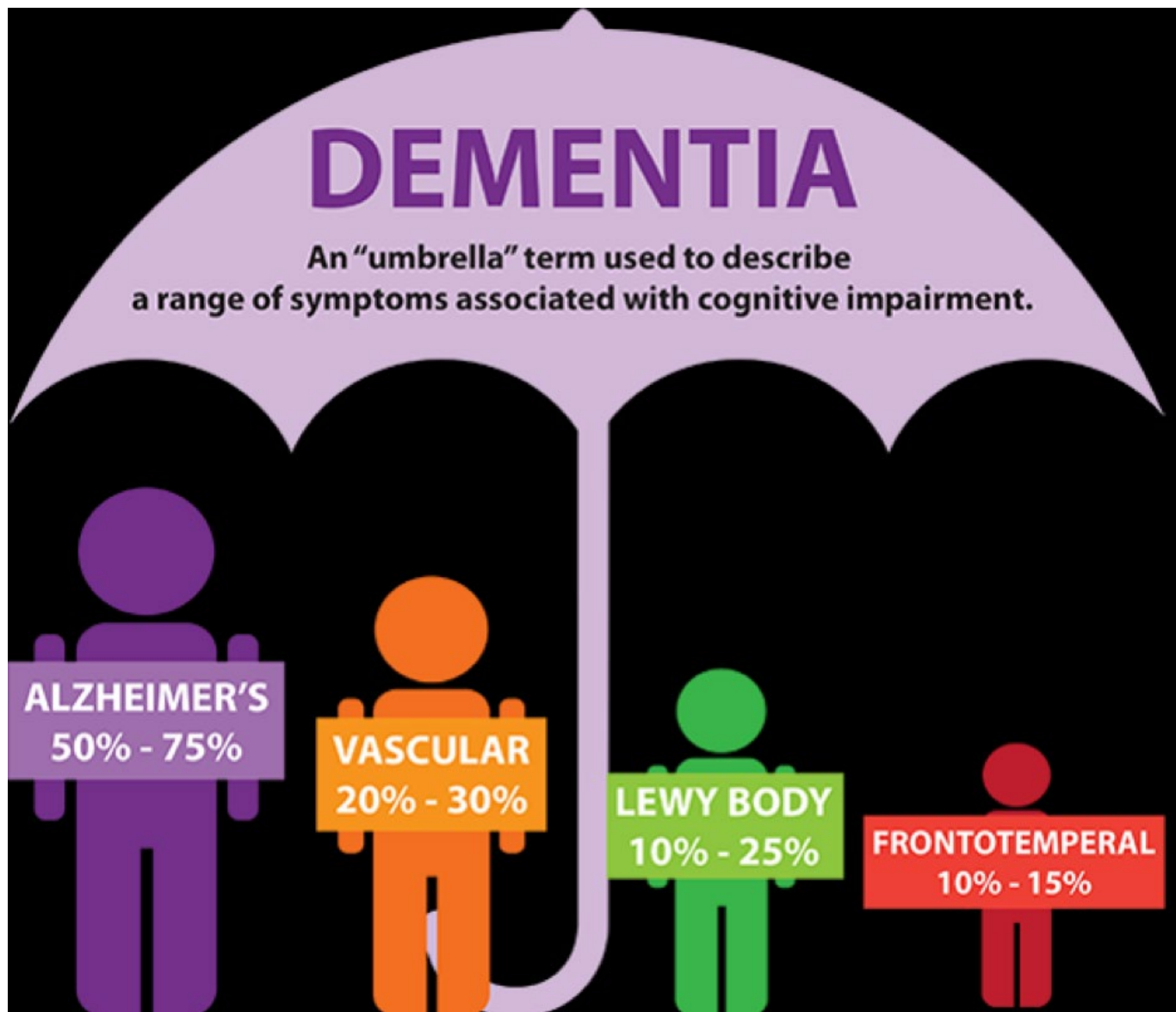


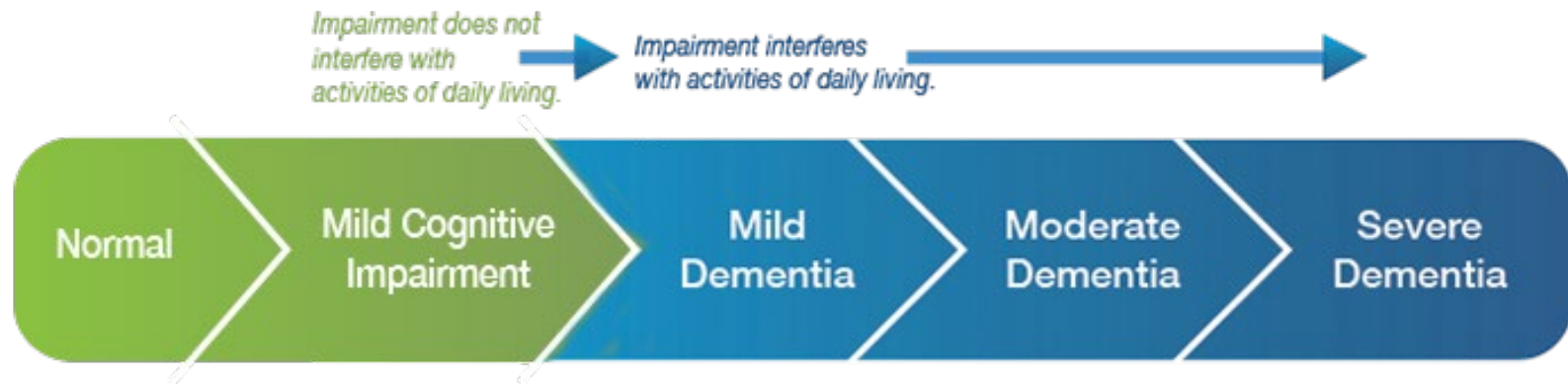
Image From: Dementia Friendly Wyoming. Available Online:

<https://dfwsheridan.org/sites/default/files/images/types%20of%20dementia.png>

The Importance of Early Diagnosis

- Autonomy- Allows you to voice your decisions in advanced care planning
- Able to take advantage of new treatments
- Different types of dementia react differently to different medications
- Allows you to be pro-active in your life anticipating upcoming challenges rather than having to be re-active to developing unexpected situations
- Can incorporate measures to slow the progression
- Embrace accommodations and make compensations to live life fully!

The Course Of Dementia- Reisberg



Stage 1: No Impairment

Stage 2: Very Mild Decline

Stage 3: Mild Decline (Mild Cognitive Impairment)

Stage 4: Moderate Decline (Early Stage Dementia)

Stage 5: Moderate Severe Decline (Moderate Dementia)

Stage 6: Severe Decline (Moderately Severe Dementia)

Stage 7: Very Severe Decline (Severe Dementia)

Image Address: <https://www.ocbrain.org/img/mcidementia.png>

The Course Of Dementia

As Alzheimer's Disease progresses, it follows a
“Functional Retrogenesis”

A reversal of normal functional development

Adult

Adolescent

Late Childhood

Middle Childhood

Early Childhood

Toddler

Infant

Hold a Job

Handle Simple Finances

Select Proper Clothing

Put on clothes Unaided

Control Bowel and Urine

Speak

Walk

Reisberg, B. et al (2002)

*Although Every Course Is Unique,
Understanding This Allows Us to Anticipate Compensations
and Accommodations For Safety, Well Being and Self-
Esteem*

The Course Of Dementia

Stage 1: No Impairment

Stage 2: Very Mild Decline- Natural Age Related Changes

Stage 3: Mild Decline (Mild Cognitive Impairment)
Other People start to notice

- Simplify Calendars and reminders
- Make sure using glasses, hearing aids etc
- Develop routines that become habit

The Course Of Dementia

Stage 4: Moderate Decline (Early Stage Dementia)

- Can no longer navigate the day by themselves
- Daily calendar with times and routines - whiteboard in the kitchen
- Keep rooms and familiar objects and clothing familiar- Label things
- Do not argue- back off and come back later
- Introduce assistive devices
- Spaced Retrieval- Pairs a Motor Memory with a need to become a habit

The Course Of Dementia

Stage 5: Moderate Severe Decline (Moderate Dementia)

- They no longer recognize they have dementia
- Do not correct them
- You lead the conversation- don't question memory
- Incorporate meaningful and purposeful activities for the person
- Maintain routines
- Walk, sing keep muscles moving
- Create a "Moment of Joy"

The Course Of Dementia

Stage 6: Severe Decline (Moderately Severe Dementia)

- Brain connection to direct muscles weakens
- Visual field has shrunk
- Give ample time to respond/ eat
- Watch for safety concerns
- Calm and quiet atmosphere
- Do with rather than Do for
- Switch to more simple sensory/music engagements

The Course Of Dementia

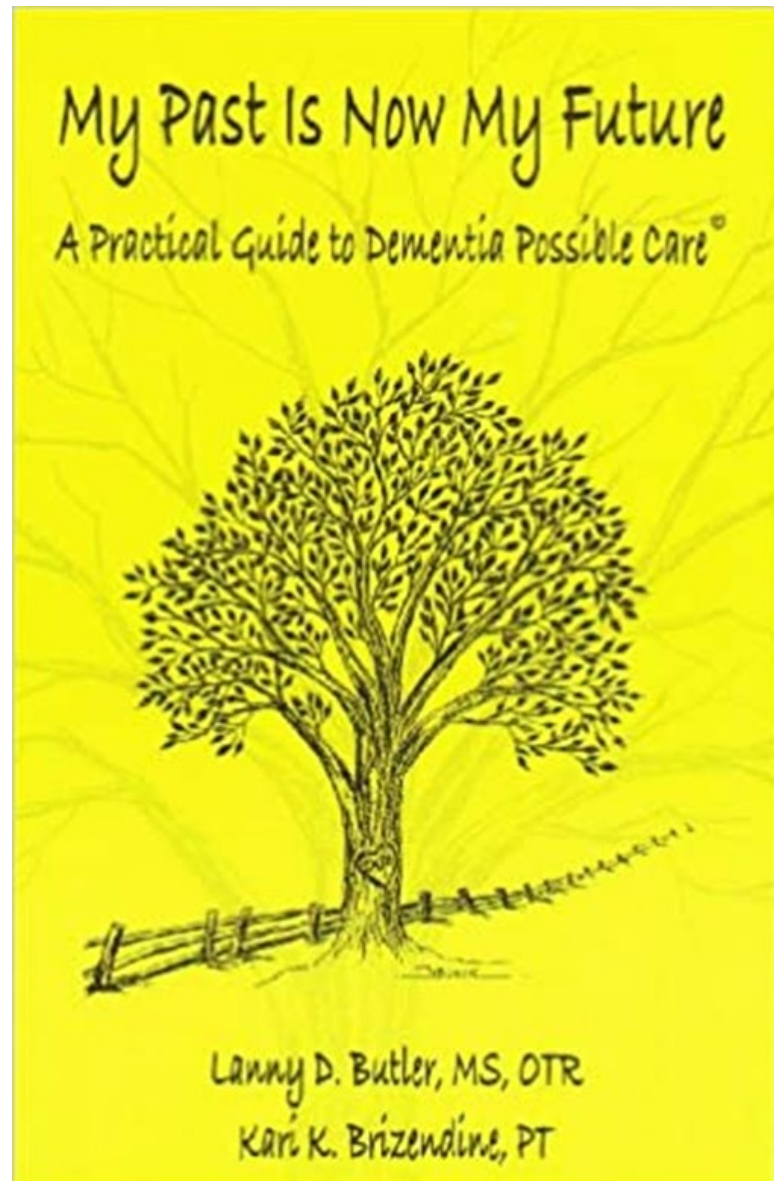
Stage 7: Very Severe Decline (Severe Dementia)

- Need help with all activities of daily living
- “If it looks good, feels good, taste good....they want it!”



Some tips taken from Kari K. Brizendine co-author: My Past is Now My Future, A Practical Guide to Dementia Possible Care

The Last Stage- Severe Dementia



Dementia Beyond Memory Concerns

Sensory Changes

Vision/Hearing/Smell/Taste/Touch

[Understanding Sensory Changes in Dementia](#)

<https://youtu.be/KHUijkp-kj0?si=Ef-8X8tcwnF72I3r>



Communication- As Words Fail

Communication does not die with words!

- Validate the feelings behind the words
- Make sure you are in their visual field
- Use simple words and phrases
- Give time to process and respond
- Offer suggestions- Yes or No or give two choices
- Non-verbal Language
- Mimic what you want them to do
- Touch
- People are disempowered when others speak for them



Reactive Behaviors

Behaviors associated with dementia are often responses to something frustrating or confusing in the environment or a physical need the person cannot express.

*Agitation/Paranoia/Hallucinations/Delusions
Restlessness/Pacing/Repetitive Motions*

- All Behaviors have a “trigger”
- NEVER argue, but validate the feeling and determine the perceived problem
- Alter the environment or your approach

Wandering Behaviors

About

PROJECT LIFESAVER

Project Lifesaver was established in April 1999 as an initiative of the 43rd Virginia Search and Rescue Company of the Chesapeake Sheriff's office.

Project Lifesaver's mission is to use technology in assisting those who care for victims of Alzheimer's and Related Mental Dysfunction Disorders (ARMD) and victims who become lost.

Project Lifesaver places personalized radio transmitters on identified persons with ARMD. These transmitters assist care givers and local emergency agencies in locating those who cannot help themselves.



How Can You Help?

Project Lifesaver is funded by private and corporate donations, budget allocation, and grants. The James City County Police Department accepts donations to support this worthy program.

Your charitable contribution is greatly appreciated.

Please make your check payable to:

James City County Treasurer

Mail your contribution to:

James City County Police
Community Projects
P. O. Box 8784
Williamsburg, VA 23187-8784

Please indicate your support of "Project Lifesaver" on your check or money order in the memo area.



Joint Area Project

The James City County Police Department Project Lifesaver program provides mutual aid to all other Project Lifesaver programs throughout the country. The Police Department underwent initial training in January 2002 in the operation and certification of the Project Lifesaver program.

The James City County Project Lifesaver program has the support of the Williamsburg Alzheimer's Association.

If you know of anyone who may benefit from the Project Lifesaver program, please contact the Community Services office for more information.

Community Services
Unit Supervisor

tel: 757-253-1800

fax: 757-229-8729

Police@jamescitycountyva.gov



And most people do not know about....

ANOSOGNOSIA

- Often mistaken for denial
- Due to brain damage causing the dementia
- There are not recognizing their challenges or impairments
 - Results in refusal for help, direction and orientation

Tips To Handle

- Make an agreement to trust a loved ones judgment
- Do Not Argue- This is their reality
- Ask them for Help or to “do it for me”
- Give a plausible reason as to why it just can’t happen right now.

Dementia: Treat as a Disease or a Disability?

Alzheimer's Disease is not caused by aging, but is associated with the aging process

Goal is to keep you as independent as possible for as long as possible; engaged with your community/surroundings and then find meaning and positive emotions in every moment

We must focus on what people still can do rather than what they cannot do!

What do you do for a person with a disability?

Make compensations!



Shifting Our Focus

Medical Model of Dementia

- Focus is on Neurological Pathology that is progressive with no cure.
- Behavioral symptoms are a result of the neurological pathology.

Psychosocial Model of Dementia

- Focus in on treating the person psychologically, socially and spiritually, and not the disease.
- Behavioral symptoms are the result of their misinterpreting their surroundings or the inability to communicate their needs to you.

Tom Kitwood -Person-Centered Care In Dementia-1997

***Who we are is either undermined or supported
by the people around us!***

'Malignant Social Psychology'

People often treat people living with dementia as if they were not there, excluding them from social events, answering for them, talking over them and “doing for” rather “doing with”. This undermines a sense of self, dignity and personhood.

This is often done unwittingly as family and staff do not understand and think they are “helping”.

The Gold Standard is Relationship Centered Care!!!

Relationship-Centered Care

“ People with advanced dementia often struggle to maintain relationships and can experience isolation and therefore, social death before their physical death”

(Alzheimer’s Society, 2013 as referred in Watson, 2019)

- Diminished Personhood and Self-Hood/Identity
- The person living with dementia can be viewed as a passive recipient or object of care- things are done for them rather than with them

Shifting Our Focus

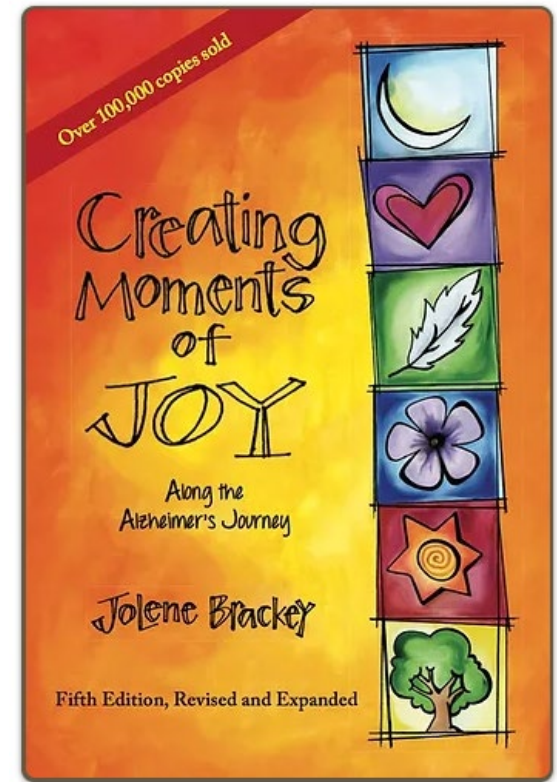
Treating the Person and Not the Disease!

Shift to focus on the person's remaining abilities and provide an environment and relationship that supports their "personhood" throughout changing cognition and functioning

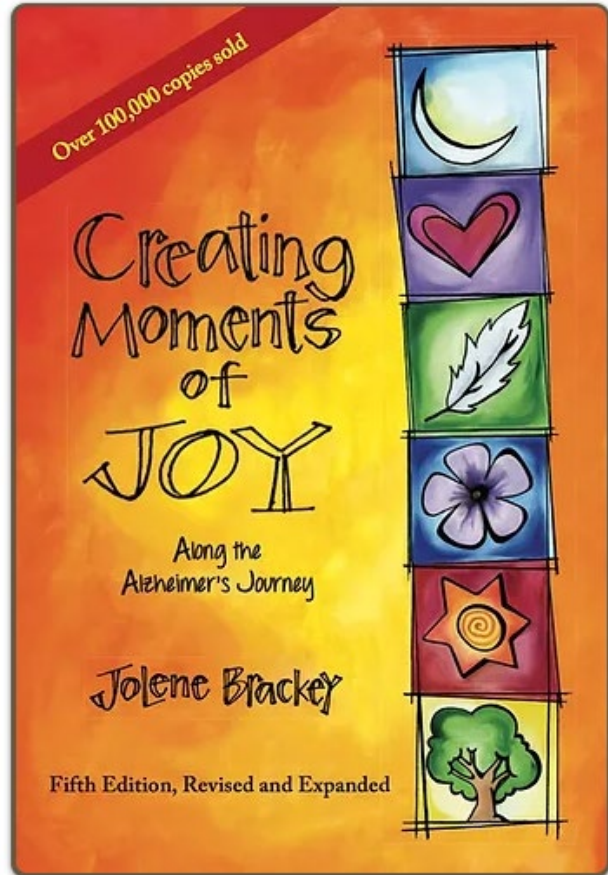
- Focus on remaining strengths
- If we know about their background, likes and listen to their opinions, validate their feelings and "do with" rather than "do for" it supports their 'personhood' and feelings of belonging
- "Care Partner" Vs. "Caregiver"

What You Can Do To Journey With Them

“ When a person has short-term memory loss, his life is made up of moments. We are not able to create a perfectly wonderful day with those who have dementia, but it is absolutely attainable to create perfectly wonderful moments—moments that put smiles on their faces, a twinkle in their eyes or trigger memories. Five minutes later they won’t remember what you did or said, but that feeling will linger.



What You Can Do To Journey With Them



- Remember Their Greatness
- Stop Correcting Them
- Live Their Truth
- Letting Go Of Expectations
- Magic Words

What You Can Do To Journey With Them

Five Ways to Acknowledge Distress

[Acknowledging Distress](#)

https://youtu.be/uGqEPlyGhCo?si=E3l9_eFkV0FO6_G



Couplehood

Shared Activities

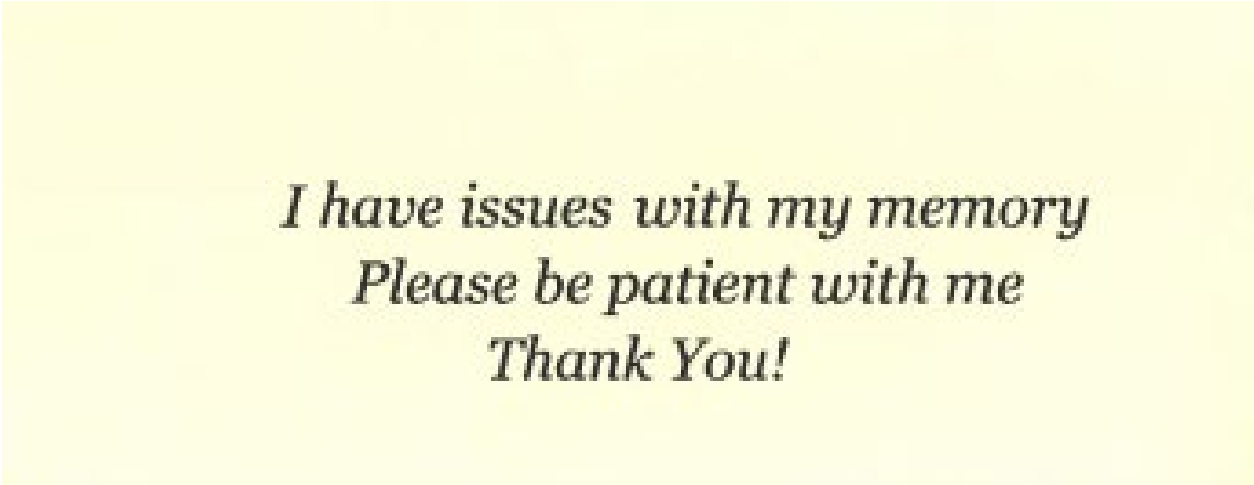
- Normalizes the relationship through engagements that are failure free like art or music where you can equally contribute as partners
- “Shared Respite” time away from just tackling the daily task duties



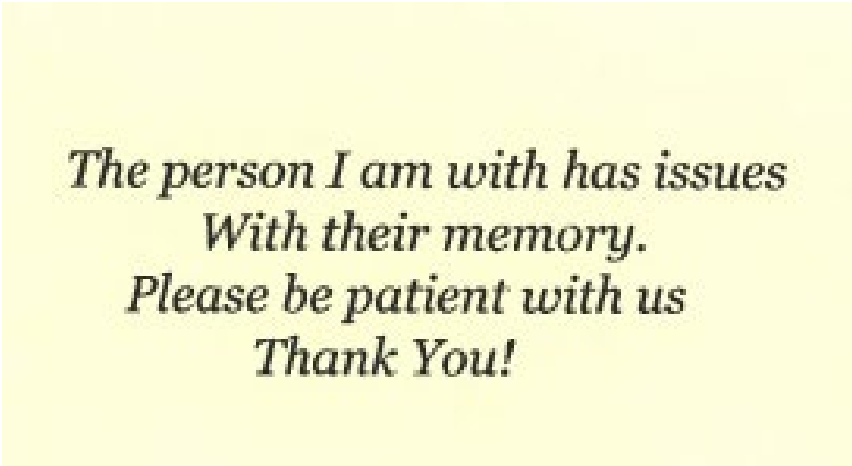
Things To Do Together

Things to do together

- Memory Café – Two in the Williamsburg Area
 1. Tabb Public Library
100 Long Green Blvd. | Yorktown, VA 23693
1:30 – 3:00 PM, 3rd Wednesday of each month
757.890.5120
 2. Williamsburg Stryker Center- Room 127
412 N. Boundary St | Williamsburg, VA 23188
1:30 – 3:00 AM, 4th Wednesday of each month
757.220.4751
- Local Library
- Look online at Colonial Williamsburg Activities -Music
- William and Mary free music concerts



*I have issues with my memory
Please be patient with me
Thank You!*



*The person I am with has issues
With their memory.
Please be patient with us
Thank You!*

*The person I am with has issues
with their memory.
Please be patient with us.
Thank you!*



riversideonline.com

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How I Made My Home Dementia Friendly

[Wendy Mitchell](#)

<https://youtu.be/k4pAaI11QeE?si=9LxolH-Ksa5jWVMM>

Technology

- Help with Orientation
- Clocks
- Reminders
- Communication Aids
- Alerts
- Telehealth
- Telecare
- Medication Administration
- Alexa
- Lighting and Temperature Control
- Safety and Security



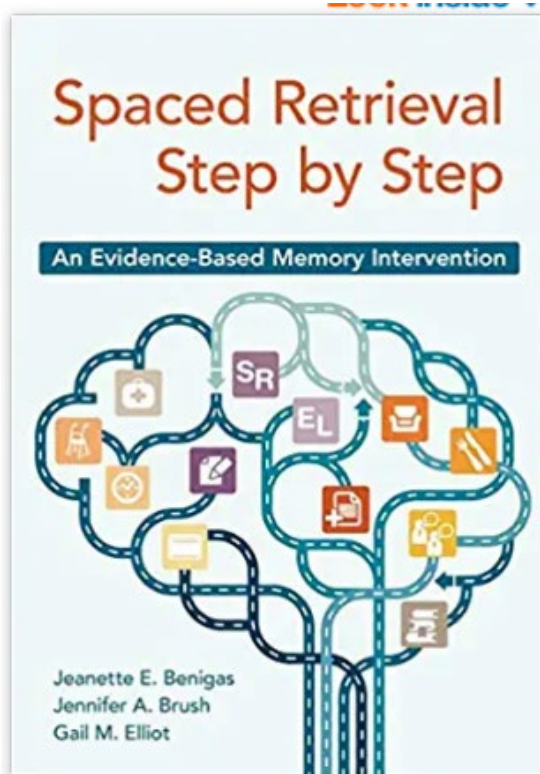


Living Well With Dementia

Cognition and Mental Stimulation

- Cognitive Rehabilitation- Personalized to your needs and desires
- Social Health is crucial for a person living with Dementia
- Cognitive Stimulation- Engages the whole brain

Spaced Retrieval



This is a memory-training strategy that is used to teach people with memory loss new or previously known information.

It pairs factual (explicit) memory with motor memory using increasing timed repetition.

Spaced Retrieval-

Develop a Question and A Response

Safety:

- What should you do before you stand up from your wheelchair? *Lock the Brakes*
- How do you sit down safely? *Reach back for the chair/bed and sit down slowly*

Activities of Daily Living:

- Where do you keep your glasses: *On the bedside table*
- What should you do before you go to bed? *Take out my dentures and place them in the cup*

Orientation:

- Where do you look when you want to know what day it is? *My calendar in the kitchen*



Spaced Retrieval

Recommended Practice Schedule

5 seconds

10 seconds

20 seconds

30 seconds

1 minute

2 minutes

4 minutes

8 minutes

16 minutes

Psychosocial Interventions

THE MAGIC OF MUSIC!

Studies show benefits of music on the mind range from stimulating cognition to improving mood

MUSIC TRANSCENDS LANGUAGE!

Triggers feelings, emotions and personal memories from a different pathway than language



Music!

Music is SO powerful! It can connect to emotion centers and connect in meaningful ways in the late stages of dementia when language and communication have deteriorated (Osman et al., 2016)

One case study explored how one spouse was able to use a meaningful song in their relationship to stimulate recognition of their relationship (Baird and Thompson, 2018).

Music- Alive Inside

[Alive Inside movie trailer](#)



<https://youtu.be/laB5Egej0TQ?si=62DPOVqch6JZGisy>

What Would You Like?

What Can We Do To Help?

- Listen!
- Connect
- You do the conversing
- Focus on their remaining abilities not what they can no longer do
- Involve in meaningful activities
 - Can you Help Me With This? - feeling that they can contribute and be appreciated!
- Create Positive Emotions
- Look for Opportunities to engage in failure-free activities that are geared for success
- Offer assistance
- Do With rather than Do For!

What Would You Like?

“Remember the person. He or she may have dementia but that shouldn’t be what defines them!

Honor the person and give them dignity by entering into their reality, patterning their day in a way that is “Their Way”.

Avoid correction of mistakes and find your sense of humor.

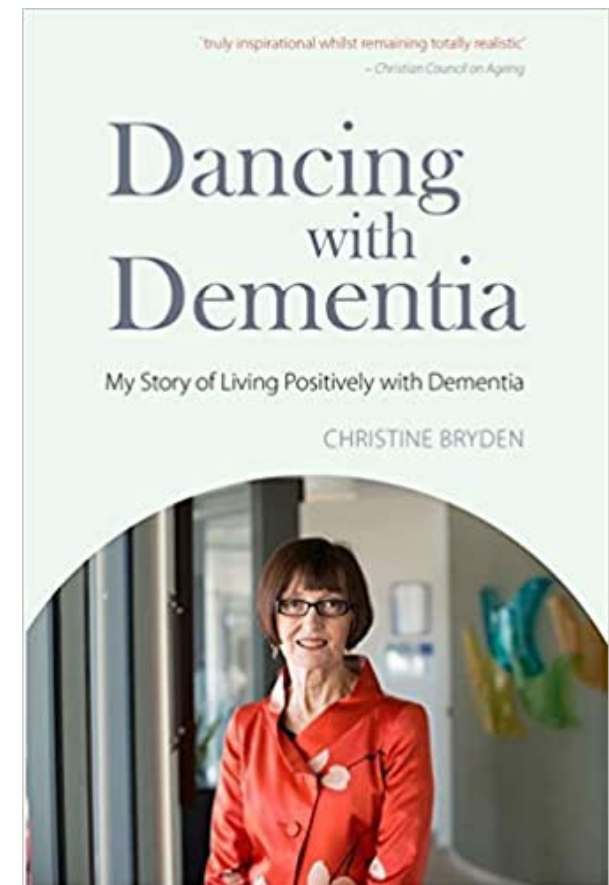
Take time for yourself so you can be in the best physical and emotional place to find joy when you are together”

Kari K. Brizendine

“ But I am surviving this journey with dementia and, rather than fighting the disability, I am adapting to it as a dance.”

“I love the imagery of a couple dancing in which we move together.”

“We sense each other’s needs, and change and adapt according to the music of the Journey with dementia.”



Living In The Moment



Questions



References And Suggested Reading

Books:

- Berry, Peter & Blunt, Deb (2020) *Slow puncture: Living well with dementia*. Great Britain: The Book Guild Ltd.
- Benigas, J. E., Brush, J. A, & Elliot, M. (2016) *Spaced retrieval step by step: An evidenced-based memory intervention*. Maryland Health Professions Press.
- Brachey, Jolene (2007) *Creating moments of joy*. West Lafayette, Indiana: Purdue University Press.
- Bryden, Christine (2005) *Dancing with dementia: My story of living positively with dementia*. London: Jessica Kingsley Publishers.
- Butler, Lanny & Brizendine, Kari (2005) *My past is now my future: A practical guide to dementia possible care*. Lynchburg, VA: Warwick House Publishing.
- Mitchell, Wendy (2018) *Somebody I use to know: A memoir*. New York: Ballantine Books.

Video Clips:

- Wendy Mitchell (2018) How I made my home Dementia-Friendly. Available online <https://youtu.be/k4pAa11QeE>
- Teepa Snow's Positive Approach To Care (n.d.) Care Partner Support Tips: Saying I'm Sorry Available online: https://youtu.be/vasnp81x63E?si=1LdY_18hpDUY4Ra5
- Understanding Sensory Changes in Dementia Available online: <https://youtu.be/KHUijkp-kj0>
- Spaced Retrieval: Available online: <https://youtu.be/FiLzX1r8RVI>

References And Suggested Reading

Web Sites

- Alzheimer's Society <https://www.alzheimers.org.uk/get-support/publications-factsheets/full-list>
List of many informational pamphlets to read including Booklets for
People Living with Dementia and Caregivers
- Technology: <https://dudley.livingmadeeasy.org.uk/>

Other References:

- Campellone, J. & Fetterman, A. (2022) What do you know about Alzheimer's Disease? University of Rochester Medical Center. Online:
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