



# *Dementia and Congregational Care*

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ANABAPTIST DISABILITIES NETWORK (ADNET)  
CHURCH OF THE BRETHREN

# Definition of Dementia

- ▶ A set of symptoms which affects one's ability to think and process information to the point it interferes with daily life
- ▶ A syndrome, not a diagnosis; there are many causes of dementia
- ▶ In the past, commonly referred to as senility and organic brain syndrome.

# Cognitive Functions

- ▶ Memory
- ▶ Orientation
- ▶ Language
- ▶ Judgment
- ▶ Personality
- ▶ Perception
- ▶ Attention
- ▶ Ability to perform tasks in sequence

# Dementia

**Dementia** = Changes in brain tissue that cause a decline in mental ability, severe enough to interfere with daily life

- ▶ Two basic types
  - ▶ Reversible dementias
  - ▶ Irreversible dementias
- ▶ Most dementias are treatable to a degree, but progressive dementias do not have a cure at this time

# Dementia is an “umbrella” term

## Reversible

- ▶ Intoxications
- ▶ Infections
- ▶ Metabolic disorders
- ▶ Vitamin deficiencies
- ▶ Major depression
- ▶ Medication reactions
- ▶ Some head injuries and brain tumors
- ▶ Normal pressure hydrocephalus

## Irreversible

- ▶ Alzheimer's Dementia
- ▶ Vascular; Multi-Infarct (strokes)
- ▶ Lewy Body Dementia
- ▶ Frontotemporal Dementia (FTLD)
  - ▶ Primary Progressive Aphasia
- ▶ Parkinson's Disease
- ▶ Hippocampal Sclerosis
- ▶ Huntington's Disease
- ▶ Progressive Supranuclear Palsy
- ▶ Creutzfeldt-Jakob Disease

# Alzheimer's Disease

- ▶ Earliest brain changes may not be seen as symptomatic
- ▶ Progressively affects new memories, causes difficulty finding words and confusion about time or place
- ▶ Dementia symptoms onset is usually after age 65; there is a familial form that strikes earlier
- ▶ Gradual decline over 8-20 years
- ▶ Other symptoms include struggling to complete familiar tasks, personality changes, misplacing things

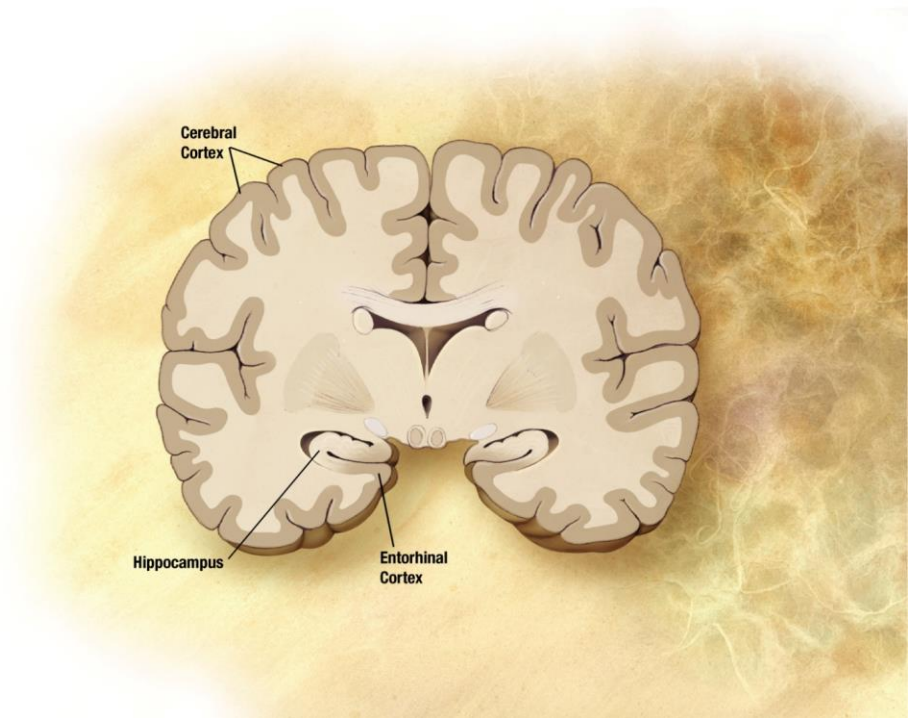
# Other common types of Irreversible Dementias

- ▶ Lewy Body Dementia – younger onset, gait issues, more rapid decline
- ▶ Vascular Dementia – on-set earlier, r/t BP, obesity, DM; with strokes & mini-strokes; symptoms depend on location in brain
- ▶ FrontoTemporal – younger onset, more rapid decline, personality changes often first
- ▶ Parkinson's – in many cases, dementia can develop in the later stages

# Preclinical Alzheimer's Disease

Changes occur many years before dementia sets in.

It is referred to as Alzheimer's Dementia when memory changes and other symptoms occur, impacting daily functioning.





# Early Stage Alzheimer's Dementia

## Early Stage:

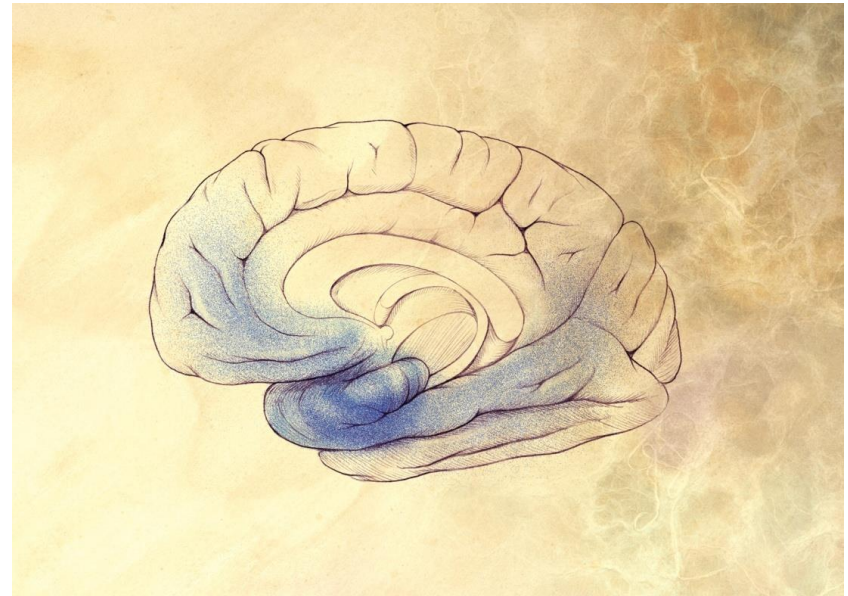
- ▶ Loss of recent memory
- ▶ Difficulty finding words
- ▶ Seeks the familiar
- ▶ Difficulty writing and using objects
- ▶ Depression, apathy
- ▶ Needs reminders for daily care



# Moderate Alzheimer's Dementia

## Middle Stage

- ▶ Chronic, recent memory loss
- ▶ More difficulty using words
- ▶ May get lost, even inside
- ▶ Difficulty using objects, purposeful movement
- ▶ Mood swings, behavioral changes
- ▶ Needs reminders with daily care



# Late Stage Alzheimer's Dementia

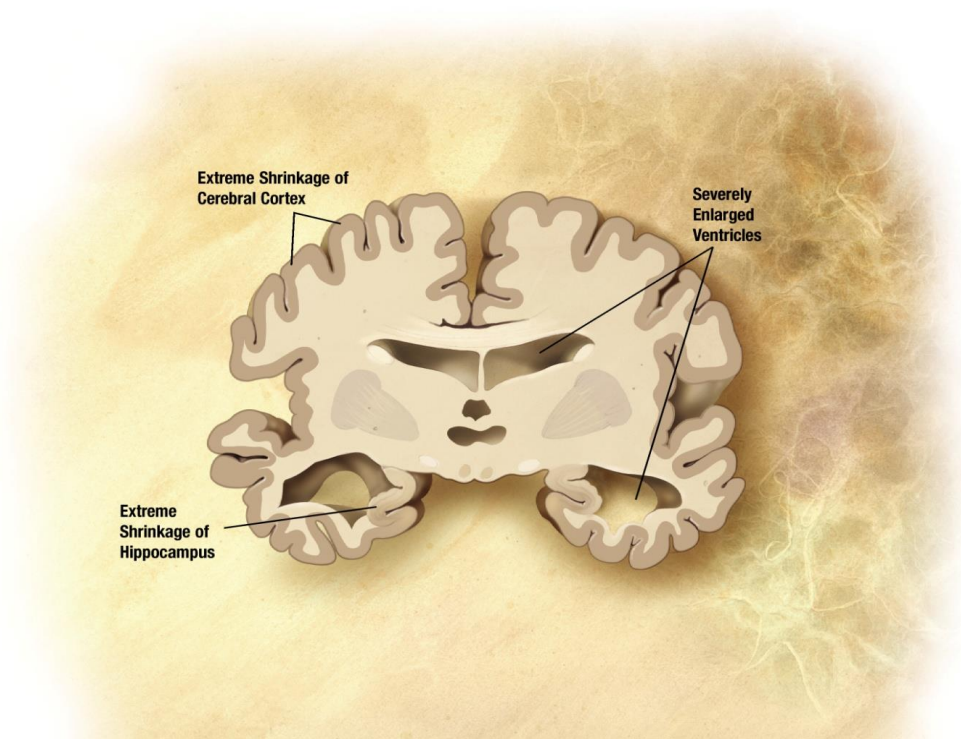
## Late Stage

- ▶ Mixes past and present
- ▶ Difficulty speaking and understanding
- ▶ Misidentifies familiar persons, places
- ▶ Slow movement, high risk for falls
- ▶ Behavior changes may occur
- ▶ BUT – *Look for connections through music, touch, non-verbal means*



# End Stage Alzheimer's Dementia

- ▶ No apparent link to past or present
- ▶ Few incoherent words
- ▶ Appears to be unaware of surroundings
- ▶ Little movement, difficulty swallowing
- ▶ Passive
- ▶ Requires total care, all areas
- ▶ BUT STILL– Look for connections through music, touch, non-verbal means



# Spirituality

## For people with dementia:

*The spiritual life of a person is not ended by dementia and can be supported and affirmed by respecting that person as a unique individual, through holistic, caring practice, helping them to experience their faith.*

**Identity**

**Belonging**

**Security**





## Statement from a faith leader:

***“Outside the door of every congregation, there are those who cannot enter, or once in, do not feel welcome.”***

How do we open the door  
and welcome them in?



## Points to consider first

How has the congregation responded to persons with dementia disorders within their midst?

Does this work?

Can this be improved upon?

Do you ask, “what brings hope, joy, meaning and peace to your life?”

# Statement from a faith leader:

*“When we think of persons with disabilities in relation to ministries, we tend automatically to think of doing something for them.*

*We do not reflect that they can do something for us and with us...they have the same duty as all members of the community to do the Lord’s work in the world, according to their God given talents and capacities.”*

(Pastoral Statement of U.S. Catholic Bishops on Persons with Disabilities, mp.17, NOD, 2001.)



# Importance of Faith/Spirituality

- ▶ Long term memory and practice
- ▶ Role of church in one's life
- ▶ Person's role in the church
- ▶ Sense of “who we are” is linked to our faith
- ▶ Structure of church and faith practices/services/rituals are comforting

# Importance of Faith/Spirituality

- ▶ Emotions and feelings remain
- ▶ Family members also impacted
- ▶ Sense of grief and loss
- ▶ Importance remains in late stages
- ▶ Listen for words or phrases
- ▶ Reassures the value of the person

*People are validated  
when we respond to their emotions.*

# Tips When Visiting Someone with Memory Loss

- ▶ You set the tone – think how you are presenting yourself – calm, gentle approach
- ▶ Be aware of your body language
- ▶ Don't talk about the person, talk to and with the person
- ▶ Gain attention, make eye contact
- ▶ Provide reassurance
- ▶ Make the setting free of distractions

# Whose Reality is It?

- ▶ The person lives in the moment
- ▶ Reality may be in the past
- ▶ Do not try to orient to the present
- ▶ Ask “How are you feeling?”
- ▶ Validate feelings – we know we’ve been heard with feelings recognized
- ▶ Straight forward, short responses - the person knows they’ve been heard.



# Language That Works: Techniques to Enhance Communication

- ▶ Use short, simple sentences
- ▶ Lower pitch for your voice
- ▶ Use concrete, familiar words
- ▶ Speak slowly, say words clearly
- ▶ Avoid open-ended questions
- ▶ Break down tasks into steps
- ▶ Help reduce choices

# Being Understood by the Person with Memory Loss

- ▶ Silence is golden – allow enough time
- ▶ Repeat words, speak slowly; allow time
- ▶ Try demonstrating visually
- ▶ Reassure if the person gets frustrated
- ▶ Try a hug or change the subject
- ▶ Distraction to another topic if the person becomes frustrated
- ▶ Use music to connect

# Understanding the Person with Memory Loss

- ▶ Listen actively and watch facial expressions and body language
- ▶ Focus on a word or phrase
- ▶ Respond to emotional tone
- ▶ Stay calm and be patient – you are setting the tone
- ▶ Use music to connect

# When Words Don't Work

- ▶ Try distraction - music, memory box, photos
- ▶ Try other communication: music, singing, signs, communication board, touch, walking, dancing
- ▶ Model what you are asking them to do
- ▶ Offer food or drink as a distraction
- ▶ Ignore outbursts and do not take personally – the person is sharing their frustration



# Activities To Do Together

Before visit, confer with family or staff, know the person!

- ▶ Familiar, that the person enjoys
- ▶ Refreshments – ok diet first
- ▶ Give choices, no more than 2 or 3
- ▶ Use faith symbols or ritual – favorite Bible, hymnal
- ▶ Sing hymns – ask their favorite before you visit
- ▶ Familiar prayers
- ▶ Scripture – favorites, translation
- ▶ Pictures
- ▶ Simple games – ask family ahead

# Behavioral Issues

- ▶ Repetitive activities
- ▶ Repeating questions or comments
- ▶ Pacing
- ▶ Disrobing
- ▶ Short temper
- ▶ Sundowning

*Use reassurance, distraction*

# Helping People with Dementia Attend Church

- ▶ Ask the family to let you know when they plan to attend
- ▶ Suggest they allow extra time to get ready
- ▶ Welcome the person and the caregiver
- ▶ Familiar object to hold – Bible, hat, etc.
- ▶ Church leaders model behavior to others
- ▶ Accessibility – Barriers can be Architecture, Communication, Attitudes

# Care of Persons with Dementia

- ▶ Listen!
- ▶ Create a supportive atmosphere
- ▶ Structure appropriate activities & have a routine
- ▶ Simplify the environment and the service
- ▶ Facilitate peer groups (for emotional support & shared activities)
  - ▶ Choirs, separate service, separate activities
- ▶ Have quiet area available – avoid over stimulation
- ▶ If you say you are going to visit – do it!

# Help for Family Caregivers

- ▶ Offer to visit, provide a meal or provide a break for the Caregiver
- ▶ Anticipate possible needs
- ▶ Know your community resources
- ▶ Promote respite services; e.g.- adult day care, in home services
- ▶ Offer individual and family support
- ▶ Encourage participation in education and support groups
- ▶ If you say you are going to visit – do it!

# Faith needs of persons with dementia

- ▶ Support needed for persons with all levels of dementia
- ▶ Faith plays a major role for strength and support for coping
- ▶ Validation of their faith experience – going to church and participating within one's abilities
- ▶ An opportunity for persons with dementia to minister to others and stay involved, not just have others do for them

# Faith needs of persons with dementia

- ▶ Support needed for both persons with dementia and their caregivers
- ▶ The need to be heard
- ▶ The need to follow faith practices of own choice
- ▶ The need to experience their faith & spirituality regularly
- ▶ The need to be involved with others in a faith setting – sense of community

# Needs and concerns of persons who do visitation

- ▶ Most frequent concern: “I do not want to say the wrong thing.”
- ▶ “Behaviors frighten me – what does it mean?”
- ▶ “John started taking off his clothes - so I left.”
- ▶ “I remember my grandmother and I do not want to set them off.”
- ▶ “What if that is me (my dad, spouse etc.) next?”
- ▶ “I need tips on how to visit and what to say/do.”



# What can my church do?

- ▶ Be welcoming and affirming
- ▶ Listen for the needs
- ▶ Ask “what can we do?”
- ▶ Help members with dementia use their talents
- ▶ Build a dementia friendly faith community – sharing what you have learned, consider trainings to help all members understand dementia
- ▶ Know resources in your community

***Resources are available!***

(slides of resources to follow)

# *Eleanor's Song*

Gardens sleep beneath the silence of deep snow;  
winter is her only season with its songs  
drifting just below the horizon of her memory.

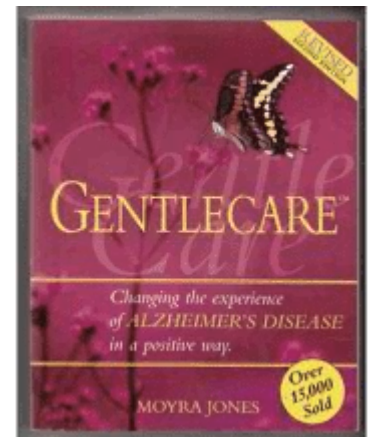
For a moment she surfaces like the sun in the morning  
singing spring over the quiet that lays deep banks  
waist high.

Then dipping back beneath her frost she grows quiet  
and song wraps her in its warmth until the gardens  
awake.

- by George Schaller

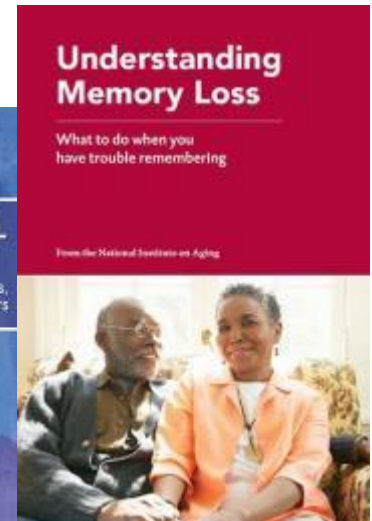
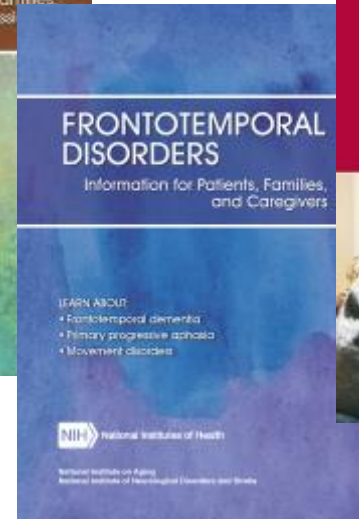
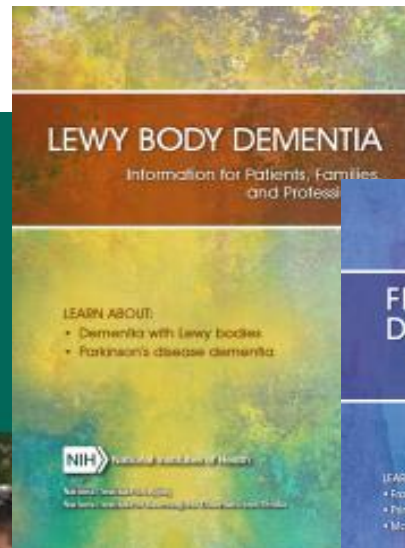
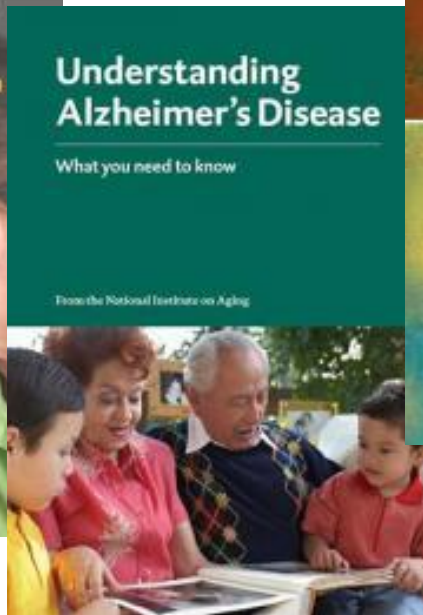
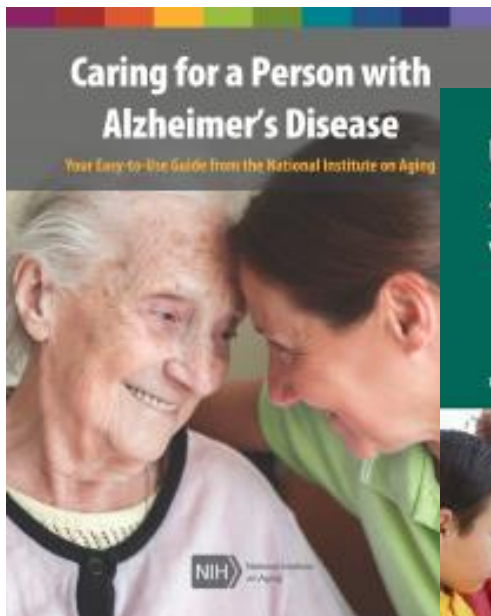
# Resources

- ▶ *Dementia-Friendly Worship: A Multifaith Handbook for Chaplains, Clergy, and Faith Communities*; Editors Lynda Everman and Dan Wendorf, 2019
- ▶ *Gentlecare* by Moyra Jones, 2007
- ▶ *Guide to Ministering to Alzheimer's Patients and Their Families*, by Pat Otwell, 2007
- ▶ *When Words Fail: Practical Ministry to People with Dementia and Their Caregivers* by Rev. Kathy Fogg Berry



# Resources from ADEAR & NIA:

- NIA publications on Alzheimer's Dementia:  
<https://order.nia.nih.gov/view-all-alzheimer-pubs>



*These and other free resources are available.*

# Next Steps After Diagnosis (resource links):

- <https://order.nia.nih.gov/sites/default/files/2020-09/next-steps-after-alzheimers-diagnosis.pdf>

*Helpful checklist  
for getting started  
after a Dementia  
diagnosis.*



# “Creating Dementia Friendly Faith Communities”

Fostering spiritual connection and meaningful engagement for those living with dementia and support for families, as we work together to stop Alzheimer’s disease

PDF with tips and guidelines for faith communities

- ▶ [Usagainstalzheimers.org/networks/faith](https://usagainstalzheimers.org/networks/faith)
- ▶ [https://www.usagainstalzheimers.org/sites/default/files/202112/UsA2\\_FaithUnited\\_One%20Pager\\_December%201%202021.pdf](https://www.usagainstalzheimers.org/sites/default/files/202112/UsA2_FaithUnited_One%20Pager_December%201%202021.pdf)

# Resource links through-

- ▶ [www.SeniorNavigator.org](http://www.SeniorNavigator.org)
- ▶ [www.disAbilityNavigator.org](http://www.disAbilityNavigator.org)
- ▶ [www.VeteransNavigator.org](http://www.VeteransNavigator.org)

Search for local resources and  
agencies by state and zip codes

*“It’s not the beginning...or even the destination  
that counts...but rather, how one navigates the  
journey.”*

# Brain and Life magazine:

<https://www.brainandlife.org>

Available in English or Spanish  
(American Academy of Neurology)







*Thank You!*