

Living with Dementia



Brain Health & Dementia Webinar Series - Session #2

February 9, 2022

Andrea Ubell MSW RSW

Director, Programs & Client Services

Luanne Campeau

Sienna Senior Living

Alzheimer Society
YORK REGION

Sienna
SENIOR LIVING

What is Dementia?

Dementia is a set of symptoms, which includes loss of memory, understanding, and judgment.

Dementia is not a disease, but a set of symptoms, that accompany a disease.

Dementia is not a normal part of aging, but risk increases with age.



Think of Dementia as an Umbrella

Alzheimer's Disease

Fronto-Temporal Dementias

Dementia with Lewy Bodies

Vascular Dementia

Mixed Dementia

Young Onset Dementia

**Late - NC
2019 * NEW**



Related Conditions

- Traumatic Brain Injury (TBI/CTE)
- Down Syndrome
- Mild Cognitive Impairment

Rare Dementias

- Corticobasal Syndrome
- Creutzfeldt-Jakob Disease
- Multiple Sclerosis
- Niemann Pick Disease (type C)
- Normal Pressure Hydrocephalus
- Parkinson Disease
- Posterior Cortical Atrophy
- Progressive Supranuclear Palsy
- Wernicke-Korsakoff Syndrome

Progression of Dementia

Early

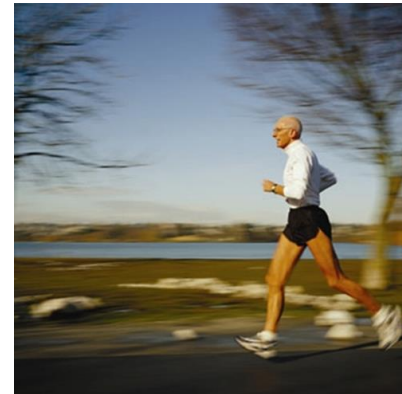
Middle

Late



Early Stage

- ❖ Forgetfulness, decreased short term memory
- ❖ Difficulty learning new things
- ❖ Needing assistance with IADLs
- ❖ Communication difficulties
- ❖ Withdrawn/apathy
- ❖ Unpredictable behaviour
- ❖ Depressed and anxious



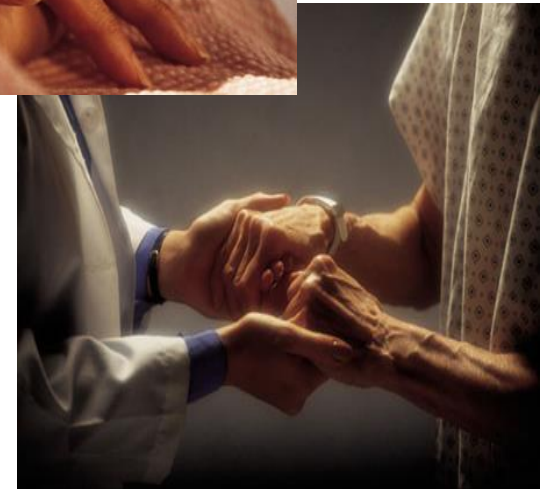
Middle Stage

- ❖ Continued forgetfulness
- ❖ Loss of personal memory/history
- ❖ Disorientation to time and place
- ❖ Assistance needed in ADL
- ❖ Dependent IADL
- ❖ Pacing or wandering
- ❖ Repetitive
- ❖ Disruptive behaviour, disinhibited behaviour
- ❖ Suspicions, delusions, confusion, anger, sadness

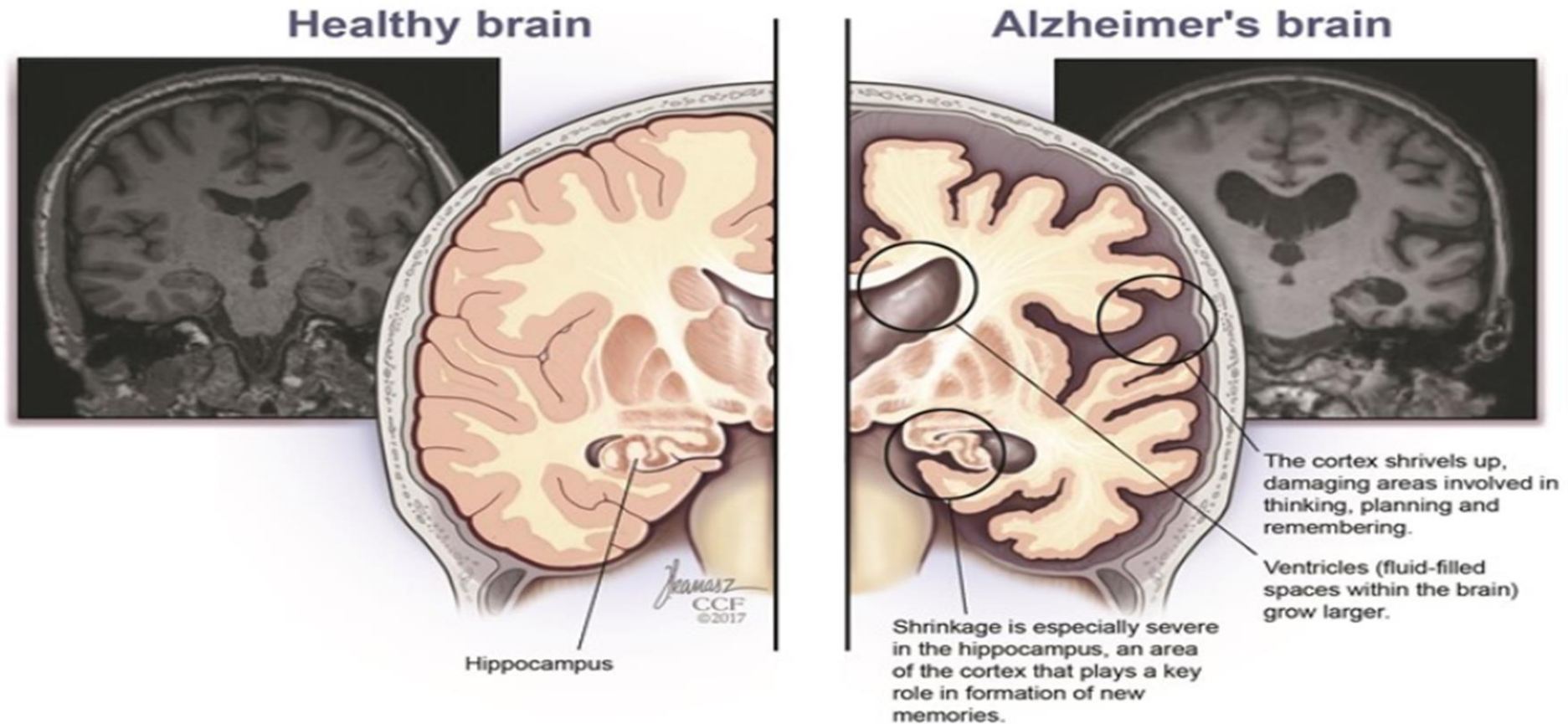


Late Stage

- ❖ Dependent in ADL
- ❖ Total Care
- ❖ Memory difficulties increase
- ❖ Speech problems
- ❖ May be bedridden
- ❖ Trouble eating and swallowing



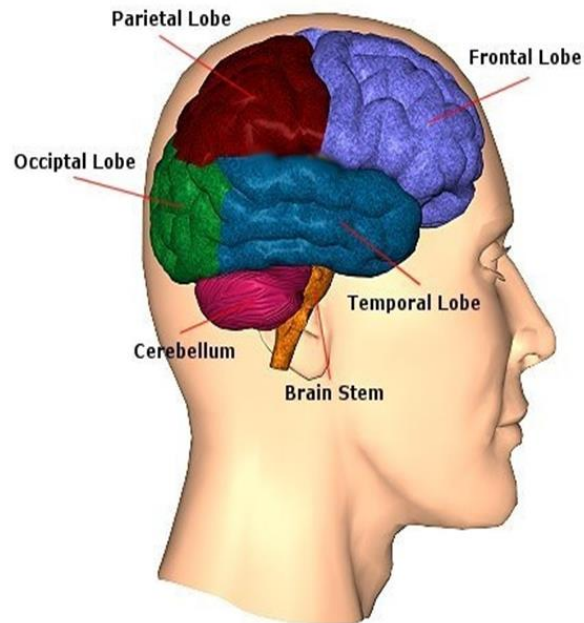
What Is Happening in the Brain?



MRI scans (gray) and illustrations (color) show the differences between a brain affected by Alzheimer's disease and a normal brain.

Changes in the Brain

Behaviours/symptoms are rooted in changes in brain



- Language
- Recognition
- Purposeful Movement
- Self-awareness
- Understanding of Environment
- Memory
- Initiation

Dementia is.....

...“a shift in the way a person experiences the world around them.”

Dr. Allen Power

- You **cannot** expect a person with dementia to change
- You **can** influence another person's behaviour
- You **can** control your own behaviour

Living with Dementia is.....

LETTING GO:

HOW IT “used to be”...

HOW IT “should be”...

HOW YOU “should be”...

“Positive Approach” www.TeepaSnow.com

Visiting Tips - THE BASICS

- ❖ Visits can be challenging
- ❖ Often a struggle to make a connection
- ❖ What works one day may not the next



Observe (body language, tone of voice)

Listen even if there are no words

Flexibility is the key

Familiarize yourself with schedule/routine

Saying HELLO....entering....

- Introduce yourself
- Third person may help
- Leave your expectations at the door
- Environment (quiet room)



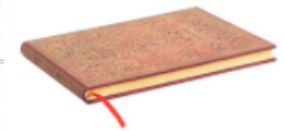
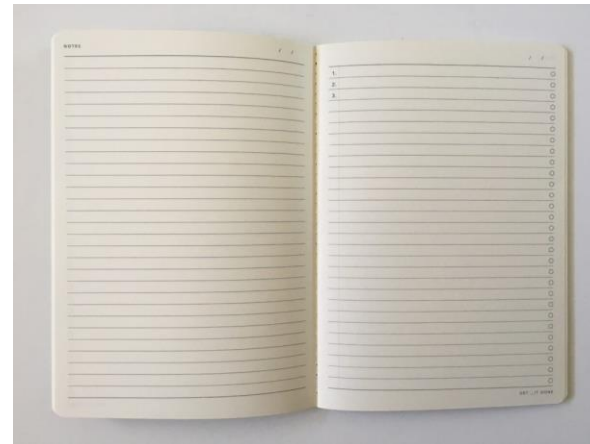
Ideas for Visiting in LTC

- Personal care – the extras
- Look at newspapers/magazines together
- Help with phone calls/birthday cards/gifts
- Facebook/Video Calls/Emails
- Plant an herb garden in window sill pots
- Exercise together
- Create a sensory box (theme)
- Go for a walk or drive
- Favourite treat or bring one to her
- Look through family pictures



Visitor/Guest Book – A Communication Tool

- Date of visit
- Visitor's name
- How you spent your time together
- When you will come again (try to be as specific as you can)
- Check first to see if okay with current protocols



Saying GOOD-BYE.....leaving.....

- Don't say "goodbye", don't make a production of your leaving
- Give a reason
- Plan departure to coincide with an event
- Have an exit plan (Resident Family Coordinator/other staff)



Alzheimer Society Canada Resources



Visiting someone with dementia? Use these tips for meaningful visits

<p>Find out the best time of day to visit. Consider during the middle of the day when the person you are visiting isn't tired yet.</p> <p>1</p> 	<p>2</p> <p>Keep in mind that what you call the person you are visiting may have to change over time. As the dementia progresses they may not recognize you as their son or granddaughter. Calling them by their first name is often the most familiar option.</p>	<p>3</p> <p>Turn off your TV and radio to make the visit peaceful and less confusing.</p> <p>Encourage the person you are visiting to make decisions about how you spend time together to enhance independence and self-esteem.</p> <p>4</p> 	<p>Play a game or work on a project together as a way to connect, create a sense of purpose, and provide something to look forward to.</p> <ul style="list-style-type: none"> • Do a jigsaw puzzle • Label photographs • Make a scrapbook • Bring both copies of the same newspaper or book so that you can both read and discuss it. <p>5</p> 	<p>Bring a child to visit, which can be fun and help maintain important relationships.</p> <p>Use these tips:</p> <ul style="list-style-type: none"> • Discuss with the child what elements are most important regarding the person you are visiting. Listen to the child's feelings and concerns. • Listen to the child that during the visit they should speak clearly, avoid arguing, and ask for help when needed. • Bring along a quiet activity that the child and the person you are visiting can do together like a jigsaw puzzle. • Get outdoors by sitting outside, going for a walk, or even helping with some weeding if there is a garden plot. • Ask the child for something they made for the person you are visiting like a picture or some homemade cookies. • Use some treats family that the person with dementia can give to the child. 
<p>Have a relaxing visit with a movie and some treats. Quiet time during a visit can be very meaningful. Remember, not all conversation is verbal.</p> <p>6</p>	<p>8</p> <p>Include others in the visit even if they can't be there physically.</p> <ul style="list-style-type: none"> • Photographs • Videos • Letters • Phone call or video call 	<p>9</p> <p>Find out if it's alright to bring a pet along. Animals can be calming, joyful and help make a connection, especially with someone who has trouble communicating.</p> 	<p>10</p> <p>Answer difficult questions the person you are visiting may have by acknowledging their feelings and reassuring them that they are safe, loved, and cared for.</p> <p>Common questions include asking where they can go home and when will someone who died a long time ago come to visit.</p>	

For more information and support, connect with your local Alzheimer Society. Visit our website at www.alzheimer.ca or call 1-800-616-8816.

Alzheimer Society Canada Resources

The screenshot shows the Alzheimer Society website interface. At the top left is the logo "Alzheimer Society". To its right is a search bar with the placeholder text "What are you looking for?" and a magnifying glass icon. Further right is an orange button labeled "DONATE NOW". Below these elements is a dark blue navigation bar with white text and dropdown arrows for "About dementia", "Help and support", "Take action", "Research", "What's happening", and "About us". Underneath the navigation bar is a breadcrumb trail: "Help and support / I have a friend or family member who lives with dementia / Making meaningful visits". The main content area features the article title "Making meaningful visits" in a large, bold font, followed by "6 min read". Below the title is a short introductory paragraph: "Whether you are visiting someone with dementia every day or just once in a while, making the most of your time together will mean a more meaningful visit for both of you!". To the right of the text is a photograph of three people: a man in a green coat, a woman in a white top, and an older man in a grey sweater who is being kissed on the cheek by the woman.

<https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/making-meaningful-visits>

Impact of Dementia Caregiving

Dementia impacts more than the person diagnosed

Constant demands lead to physical/emotional fatigue

Normal routines are disrupted

Behaviours of persons diagnosed can be frustrating/stressful

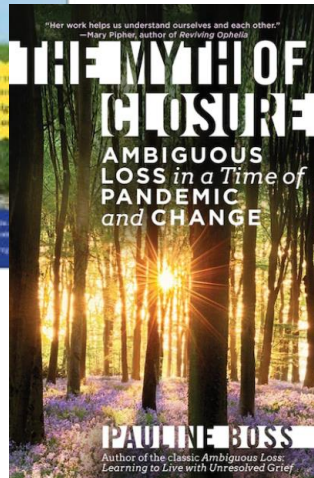
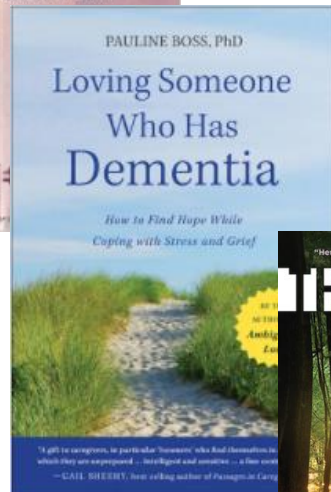
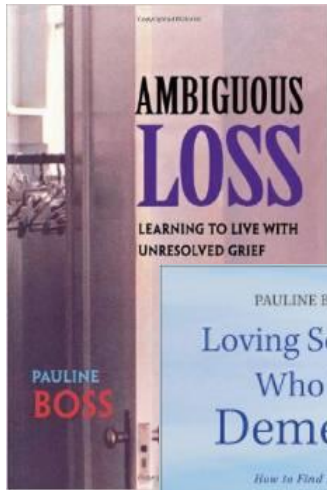
Number/kind of problems for family caregiver can be overwhelming



Impact of Dementia Caregiving

- Sleep deprivation
 - Poor eating habits
 - Failure to exercise
 - Failure to stay in bed when ill
 - Postpone own medical appointments
 - Increase risk of using poor coping mechanisms like drinking, smoking, medications
- Fear
 - Depression
 - Frustration/despair/helplessness
 - Isolation/loneliness
 - Resentment/anger
 - Embarrassment
 - Guilt
 - Grief

The Unspoken Partner on the Dementia Journey



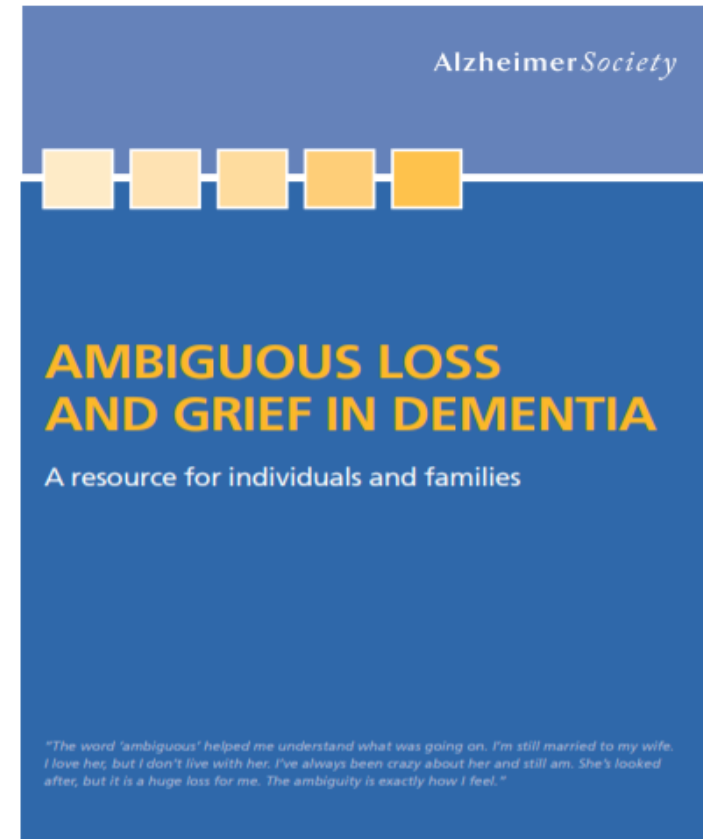
- Grief – the unspoken dance partner
- Loss is a definite aspect of the dementia journey
- Special kind of loss
- Loss without closure, loss that is unclear
- Loss when the person is physically there but not mentally and emotionally present as they used to be – presence and absence
- Leaves the person searching for answers
- Complicates, stresses the grieving process
- Limbo (frozen or life put on hold)
- Confuses relationships and prevents one from moving on
- **Not often recognized or understood**

Alzheimer Society Canada Resources

Updated 2019, Alzheimer Canada


“The word “ambiguous” helped me understand what was going on. I’m still married to my wife, I love her, but I don’t live with her. I’ve always been crazy about her and still am. She’s looked after, but it is a huge loss for me. The ambiguity is exactly how I feel.”

[https://alzheimer.ca/sites/default/files/documents/ambiguous-loss-and-grief_for-individuals-and-families_1.pdf](https://alzheimer.ca/sites/default/files/documents/ambiguous-loss-and-grief-for-individuals-and-families_1.pdf)



What Can YOU Do ?

- Learn about the disease
- Be realistic about the disease
- Can not stop the impact of a progressive illness but you can equip yourself with coping skills
- Recognize when you are in trouble
- **Don't do this alone reach out and get help (support groups/Resident Family Coordinator/Social Worker)**



**GOD,
GRANT ME THE SERENITY
TO ACCEPT THE THINGS I
CANNOT CHANGE,
THE COURAGE TO
CHANGE THE THINGS I
CAN, AND THE WISDOM
TO KNOW THE
DIFFERENCE..**

Resilience

- Pacing – dementia care is a marathon not a sprint
- Peer Support – support groups, others experiencing what you are experiencing is important
- Mindfulness, prayer, a time for quiet
- Breathe
- Get outside in nature
- Activities that replenish you along the journey
- Nourishing activities every day
- You do not have to visit every day
- **ARE YOU PREPARED FOR THE NEW DANCE?**



Thank You for Your Time

For more information, or if you have questions about Alzheimer's disease or other dementias, please contact us.



Andrea Ubell, MSW RSW
Director, Programs & Client Services

1-888-414-5550



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YORK REGION