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Alzheimer's 101: An Overview for Healthcare Professionals

Megan L. Malone, M.A. CCC-SLP Jennifer Loehr, M.A. CCC-SLP



Speaker Bios

Megan Malone is a speech-language pathologist working as a clinical faculty member in Kent State University's Department of Speech Pathology & Audiology and as a clinician and consultant in home health care. She previously worked for as a senior research associate and lead trainer at Myers Research Institute, in Cleveland, OH where she oversaw federally/privately funded grants focused on implementing interventions with older adults with dementia. She is the co-author of the book, "Here's How to Treat Dementia" (Plural Publishing, 2013), the co-author of the textbook chapter, "SLP Services in Home Health Care" in "Medical Speech Language Pathology Across the Care Continuum: An Introduction", and "has spoken numerous times at the annual conventions of the American Speech and Hearing Association, Gerontological Society of America, American Society on Aging, and the Alzheimer's Association, along with several state speech and hearing conventions. She has published articles in the Journal of Communication Disorders, Alzheimer's Care Quarterly, The Gerontologist, and Dementia.



Speaker Bios

Jenny Loehr is a speech-language pathologist with over 30 years' experience working in adult neurology. She has presented at over 30 state and national conferences and online continuing education programs on the topic of dementia and healthcare management including the American Speech and Hearing Association, the National Association of Home Health and Hospice and Leading Age of Texas. She is the co-author of the book "Here's How to Treat Dementia" (Plural Publishing 2013), the co-author of the textbook chapter," SLP Services in Home Health Care" in "Medical Speech Language Pathology Across the Care Continuum: An Introduction", and has also published articles for the ASHA Leader and the Journal of Communication Disorders. She currently works for a large national home health and hospice company providing training, education, and mentoring for physical, occupational, speech language pathologists and nurses in home health and hospice policy, procedures, compliance and program implementation.



Disclosures

- Presenter Disclosure: Megan Malone Financial: Megan Malone was paid an honorarium for this presentation. Megan is is the coauthor of the book, "Here's How to Treat Dementia," for which she receives royalties, and has received grant funding for research related to this topic. Non-Financial: No nonfinancial relationships to disclose. Jenny Loehr Financial: Jenny Loehr was paid an honorarium for this presentation. Jenny is the co-author of the book, "Here's How to Treat Dementia," for which she receives royalties. Nonfinancial: No nonfinancial relationships to disclose.
- Content Disclosure: This learning event does not focus exclusively on any specific product or service.
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Learning Outcomes

After this course, participants will be able to:

- Define Alzheimer's disease and related disorders and describe their progression.
- Describe strategies for communicating with patients with Alzheimer's disease and related disorders.
- Describe methods for managing behavioral challenges related to Alzheimer's disease/dementia.
- Identify current interventions for patients with Alzheimer's/dementia to promote independence and participation in activities of daily living.
- Describe ways to support families/caregivers of persons with Alzheimer's/dementia.





Part I: Understanding Dementia & Alzheimer's Disease



Question to Consider:

"On a scale of 1 to 10, How would you rate your level of knowledge of Alzheimer's disease or dementia?"



Question to Consider:

"What do you consider to be your current role in working with Alzheimer's disease or dementia?"



Alzheimer's Disease and Dementia Facts

- More than 6 million Americans are living with AD
- 1 in 3 seniors dies with AD or other dementia
- AD kills more people than breast cancer and prostate cancer combined
- In 2023, AD and other dementias will cost the nation \$345 billion
- Over 11 million Americans provide unpaid care for people with AD and other dementias
- Between 2020 and 2030 1.2 million additional direct care workers will be needed to care for individuals with dementia (Alzheimer's Association 2023 (1))



Dementia Defined:

- It is not a single disease
- It is an overall term to describe a collection of symptoms
- Diseases grouped under the general term "dementia" are caused by abnormal brain changes.
- Dementia causes a decline in cognitive skills severe enough to impair daily life and independent functioning.

(Alzheimer's Association, 2023 (2))





Dementia Diagnosis

- There is no one test to determine dementia
- Dementia is not a normal part of the aging process
- Diagnosis is based on:
 - Review of Medical History
 - Laboratory tests
 - Physical examination
 - Assessment of characteristic changes in thinking, day to day functioning and behavior
 - Structural imaging (CT or MRI)
 - Neuropsychologist testing
- A specialist may need to determine the exact cause or dementia diagnosis (NIA, 2023)



Dementia Diagnosis

- Dementia is a group of symptoms that can include:
 - Language disturbances (e.g., aphasia, dysphasia, anomia)
 - Problematic behaviors (e.g., repetitive questioning, wandering)
 - Difficulties with activities of daily living (e.g., dressing, personal grooming)
 - Personality disorders (e.g., disengagement, aggressive behaviors)





Causes

- Nutritional deficiencies
- Infections
- Subdural hematomas
- Poisoning
- Anoxia
- Brain Tumors
- Metabolic changes
- Vitamin B12 deficiency
- Chronic Alcohol Abuse
- Depression



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(NIA, 2023)



General Symptoms

- Memory Impairment that disrupts daily life
- Challenges in planning or problem solving
- Difficulty completing familiar tasks
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Poor judgment
- Withdrawal from work, family or social activities
- Changes in mood and personality
- Misplacing things and losing the ability to retrace steps



Dementia Types/Symptoms:

- Frontotemporal Dementia
 - Abnormal amounts or forms of tau and TDP-43 proteins accumulate inside neurons in the frontal and temporal lobes
 - Rapid progression
 - Behavioral and Emotional Symptoms:
 - Difficulty planning and organizing
 - Impulsive behaviors (hallmark symptom)
 - emotional flatness or excessive emotions
 - Movement and Language Symptoms:
 - Shaky hands
 - Problems with balance and walking
 - Difficulty with expressive and receptive communication

(NIA, 2023)





Dementia Types/Symptoms:

- Lewy Body Dementia
 - Abnormal deposits of the alpha-synuclein protein called "Lewy bodies" affect the brain's chemical messengers
 - Similar to Parkinson's Dementia
 - Rapid progression
 - Symptoms:
 - Inability to concentrate, pay attention or stay alert
 - Disorganized or illogical ideas
 - Muscle rigidity
 - Poor coordination
 - Flat affect
 - Insomnia
 - Visual hallucinations (Hallmark symptom)



Dementia Types/Symptoms:

- Vascular Dementia
 - Conditions such as blood clots disrupt blood flow in the brain
 - Common with history of stroke
 - Slower progression
 - Symptoms:
 - Memory Loss
 - Expressive/Receptive language deficits (Hallmark symptom)
 - Trouble following instructions or learning new information
 - Difficulty understanding written language
 - Hallucinations
 - Poor judgment

(NIA, 2023)





Dementia Types/Symptoms

- Mild Cognitive Impairment
 - Amnestic MCI: Primarily affects memory
 - Non-amnestic MCI: Affects other areas of cognition
 - Likely to develop into Alzheimer's disease
 - Individuals with MCI have twice as many hospital stays as other older adults
 - Symptoms:
 - Increased forgetfulness
 - Losing train of thought
 - Trouble following conversations, instructions or making decisions
 - Poor judgment
 - Depression, lack of interest, increased temper or aggression



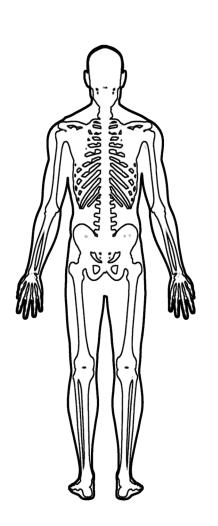
Dementia Types/Symptoms

- Alzheimer's Disease
 - Abnormal deposits of proteins that form amyloid plaques and tau tangles throughout the brain
 - Typically slow progressing
 - Biggest risk factor is age
 - Mild to Severe Symptoms:
 - Memory impairment that disrupts daily life
 - Challenges in planning or problem solving
 - Difficulty completing familiar tasks
 - Confusion with time or place
 - Trouble understanding visual images and spatial relationships
 - New problems with words in speaking or writing
 - Change in mood or personality
 - Withdrawal from work, family or social activities
 - Misplacing things and losing the ability to retrace step



Physical Considerations

- Swallow dysfunction
- Malnutrition
- Dehydration
- Gum/Dental Disease
- Infection
- Gait Dysfunction
- Heart disease
- Sleep disturbance
- Depression





America's Response:

Per the Alzheimer's Association:

- Only 4 in 10 Americans would talk to their doctor right away when experiencing early memory or cognitive loss.
- 7 in 10 Americans would want to know early if they have Alzheimer's disease if it could allow for earlier treatment

(Alzheimer's Association, 2023 (1))



Part II: Understanding Memory



Question to Consider:

"Is having a memory problem an expected part of normal aging?"





Circumvent the Deficits

- Individuals with dementia cannot learn or remember information.
 - Persons with dementia do have weaknesses in the areas of learning and memory BUT a number of strengths exist as well
 - Ability to learn procedures
 - Ability to read
 - Research has shown that the learning of information and its retention depends heavily on how it is presented and practiced

KEY: Be aware of the weaknesses but FOCUS ON THE STRENGTHS!!!



Understanding Memory

- Memory is the continued process of information retention over time.
- Three main processes for how memory works:
 - Encoding:
 - Process for how information is learned. Dependent on attention.
 - Organizing incoming information (visually: how something looks; acoustically: how it sounds; semantic: what it means; tactile: how it feels). Organizing information in a meaningful way
 - Repetition, rehearsal, mnemonics (e.g., ROY G BIV (colors of rainbow).

Bok Center for Teaching and Learning, n.d.





Understanding Memory

- Storage: how long encoded information is retained.
 - Short term memory: only lasts between 15-30 seconds; 5-9 pieces of information
 - Long term memory: immense storage capacity
- Retrieval: accessing stored information.
 Information stored in short term and long-term memory are retrieved differently.
 - Short term: order in which it's stored (e.g., phone number)
 - Long term: retrieved through association

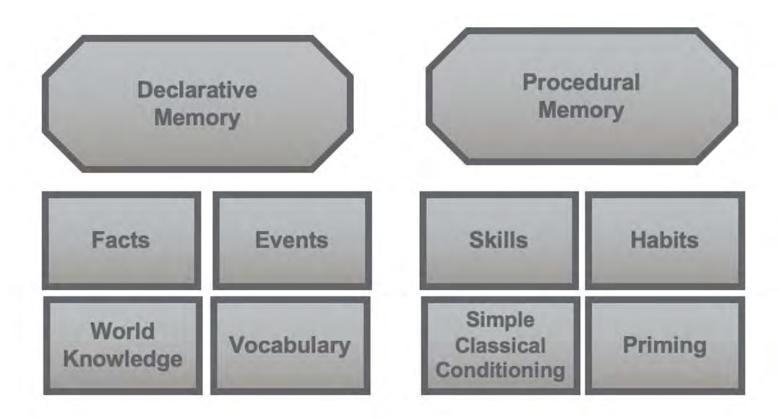


Understanding Memory

- Short term memory: Primarily affected first with Alzheimer's and other dementias
- Long term memory: can be affected by dementia over time in both storing information and retrieving it but aspects can be relatively spared over the progression of dementia.
 - Declarative memory: conscious recollection of particular facts and events
 - Procedural memory: memory for learning & executing tasks (e.g., reading; tying shoes, etc.)



Learning & Memory in Dementia





Part III: Treatment Trends & Communication Strategies





Question to Consider:

"What are some treatments or strategies you have used or seen used with persons with dementia or Alzheimer's disease?"



Treatment Option Overview

- Drug and non-drug options for treatment
- Consult health care professional to navigate the many options.
- Patient needs may change over time as disease progresses.
- Stages:
 - Early/Mild:
 - Symptoms not as apparent (e.g., some difficulty thinking of words, losing objects, trouble organizing & planning
 - Middle/Moderate:
 - Longest stage. More pronounced difficulties overall (e.g., forgetful of personal history or events, confusion, getting lost, etc.)
 - Late/Severe:
 - Increased severity of symptoms (e.g., require consistent care, difficulty communicating and responding to environment



Treatment Option Overview

- There are approved medications by the Food and Drug Administration (FDA) for Alzheimer's disease.
 - Drugs that ease symptoms (target memory issues, behavioral changes, sleep disturbances, etc.)
 - Drugs that slow the progression (IV infusion therapy either every two weeks (Lecanemab (Leqembi®) or once a month (Aducanumab (Aduhelm®)
 - Medications for Dementia from Alzheimer's Association: https://www.alz.org/alzheimers-dementia/treatments/medications-for-memory

Alzheimer's Association, 2023 (4)





Treatment Option Overview

- Behavioral Treatment Options:
 - "The behavioral and psychologic symptoms of dementia include psychosis (i.e., delusions and hallucinations), aggression, agitation, irritability, anxiety, depression, apathy, mood lability, disinhibition, intrusiveness, impulsivity, restless motor disturbances, and sleep disturbances" (Scharre, 2021; Kales et. al, 2015; Cummings et. al, 2020; Ballard et. al, 2020).
 - Behavioral or non-pharmacologic approaches include those that focus on the individual, those that focus on the caregiver, and those that focus on the environment (Scharre, 2021).



Behavioral Treatments for Dementia

- Activity-Focused Dementia Care
 - Incorporates meaningful activities into the daily lives of persons with dementia
 - Part of person-centered care (focuses on individual wants/needs)
 - Interactions are based on knowledge and deep respect for care recipients as human beings (similar to Montessori philosophy)
- Abilities Focused/Strength-Based Care
 - "Caregivers deliberately identify and encourage the use of an individual's retained skills and capacities including physical, motor, cognitive, emotional, social and communicative."
 - "The goal of abilities-focused care is to compensate for dementiarelated problems and limitations and to focus on using remaining abilities to allow for successes."

(Wood, n.d.)





Behavioral Treatments for Dementia

Can be Direct or Indirect

Direct

 When professionals intervene directly with individuals or group using an intervention

Indirect

 Professionals train caregivers in an intervention, modifies the environment, or develops activities to maximize function

Mahendra & Hopper, et. al, 2008







Behavioral Treatments for Dementia

- Treatments focused on the individual:
 - Increasing sensory stimulation (e.g., music and art therapy)
 - Communication strategies (e.g., reassurance, empathy, direct communication; validation)
 - Personalized activities (e.g., Montessori; Reminiscence)
 - Use of visual and graphic supports (e.g., memory books)
 - Increasing and maintaining routines
 - Redirection to alter patient focus



- Validation Therapy:
 - Process of communicating with a disoriented elderly person by validating and respecting their feelings in whatever time/place that is real to them, even if it doesn't match our reality. (Vanderslott, 1994)
 - Direct contrast to Reality Orientation
 - Goal is to understand the meaning behind a person's behavior & validate their beliefs
- Reminiscence Therapy:
 - Focuses on facilitating the patient with dementia to remember experiences in his/her life and assisting in that person sharing those memories with others (Grasel, Wiltfang & Kornhuber, 2003)
 - Frequently done in groups in facility settings
 - Promotes social interaction, conveying positive emotions, & promoting self-awareness (Hodgson & Schweitzer, 1999)



- Montessori-Based Programming
 - Programming method that use Montessori educational principles to provide constructive engagement, meaningful activity, and practice of skills to older adults.
 - Uses principles from the Montessori classroom to help older adults maintain independence and learn new skills.
 - Camp and other researchers have documented the use of this
 programming method with persons with Alzheimer's Disease and have
 found that it increases overall participation in activities, as well as rates
 high in staff satisfaction (Camp, 2002; Skrajner et al., 2007).
 - International Implementation: France, Australia, Singapore, Spain, Ireland,
 Switzerland and many other countries (Antenucci & Roberts, 2017)
 - High levels of staff satisfaction found in using method



- Visual & Graphic Cues:
 - The use of visual/graphic cues has been widely documented as a successful treatment strategy with persons with dementia (Bourgeois & Hickey, 2009; Bourgeois, et. al. 1997; Bourgeois, 2007).
 - Memory Books and Wallets are also useful treatment tools for the therapist working with dementia patients (Bourgeois, 1992).
 - Memory Books and Wallets utilize meaningful pictures, and short, clear, concrete sentences to describe the pictures to help the patient with dementia recall important personal information, routines, etc.



- Spaced Retrieval Training:
- Goal of using SRT:
 - To enable individuals to remember information for long periods (days, weeks, months, years) so that they can recall important information or strategies.
 - Teach patients strategies that compensate for memory impairments, using procedural memory, including reading and repetition priming.
 - Consists of a prompt to elicit a response (e.g., "What should you do before you stand?" Answer: "Lock my wheelchair breaks".)
 - Can improve patient safety (transfer strategies, swallowing strategies, precautions), recall of meaningful information (family member names, orientation information) and complete daily functions (completing ADLs, taking medications, paying bills, attending appointments).



Behavioral Treatments for Dementia (Caregiver & Environmental)

Caregiver focused:

- Education-based
- Aspects focus on Person Centered Care, communication strategies, caregiver mental health support, understanding and managing behaviors

Environmental:

- Reducing overstimulation and understimulation in environment, safety issues, lack of routines
 - Overstimulation: address clutter, excessive noise, people
 - Understimulation: lack of interesting things in environment to look at or engage with
 - Sensory deprivation: accounting for visual & hearing changes
 - Safety: sharp or dangerous materials in the environment; opportunities for patient's to leave environment (elopement) (Scharre, 2021)





- Depends on stage of disease the patient is in (i.e., early, middle or late).
- Early:
 - Don't assume about person's ability to communicate
 - Include person in conversations
 - Speak directly to person
 - Allow person time to respond and process information

Alzheimer's Association, 2023 (5)





Middle:

- One on one communication is best
- Speak slowly & clearly; maintain eye contact
- Allow for response time
- Support communication with visual supports

Late:

- Approach from person's front; identify yourself
- Treat person with respect & dignity; do not talk down to person
- Try to infer emotion by tone of person's response







- Communication/Conversational Approaches
 - Verbal compensatory strategies (e.g., describing or spelling a word that cannot be recalled or asking a clarifying question to help improve understanding of information
 - Non-verbal compensatory strategies (e.g., using pointing, gesturing, or facial expression to help a patient communicate wants, needs, pain, etc., when a patient is unable to do so verbally)
 - Written compensatory strategies (e.g., writing down a word or using one's finger to spell a word when unable to verbally express the word
 - (Hinckley, Bourgeois, & Hickey, 2011)



- Communication/Conversational Approaches
 - Structuring conversations/interactions to utilize questions that incorporate choice (e.g., Saying, "Would you like spaghetti or pot roast for dinner tonight?" rather than "What would you like for dinner tonight?")
 - Asking questions that can be answered with a simple "yes or no"
 - Using open-ended questions that allow people to share their opinion (e.g., Asking "How do you feel about the food served here?" rather than "What did you have for breakfast?")

Hinckley, Bourgeois, & Hickey, 2011



Part IV: Supporting Patients in Activities of Daily Living & Care Planning





Keys to Success:



- Learn about <u>who</u> the patient is (Behavioral patterns)
- Give back control
- Educate as much as possible
- Include the patient in decision making
- Praise Praise Praise! (positive reinforcement)
- Validate feelings
- Keep it simple
- Ask questions that offer choices or allow the expression of opinions

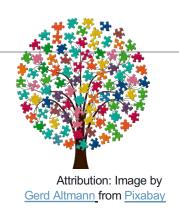


Optimize the Treatment Environment

- Always end on a successful note
- Eliminate distractions
 - Turn off the TV
 - Set a comfortable mood
 - Build a consistent routine (familiarity)
- Use meaningful tools
 - Photo albums
 - Music
 - Pets
 - Hobbies or Interests



Holistic Approach



- Best approach to care of persons with dementia includes support from multiple sources working together
- EVERY staff member of a facility is a part of the dementia care team
 - Physician
 - Therapy Team
 - CNAs
 - Dietician
 - Social Worker
- Team members can work together to develop interventions, counsel and educate patients & families, etc.

Loehr & Malone, 2013



Care Plan Development

- Keep the goals realistic
- Keep the goals simple
- Long term treatment is not an option
- Use the environment as your "toolkit"
- Build on the patient's strengths
- PATIENT SAFETY IS THE PRIORITY
 - Safe and adequate nutrition and hydration
 - Eliminate falls
 - Mitigate injury due to wandering
 - Reduce aggressive behaviors



Care Plan Development

- Build an education moment into every treatment
- Education should be documented thoroughly
- Include "as evidenced by" in your goal writing
- Include the patient/caregiver in goal planning
- Goals should be measurable, attainable and functional
- Goals for dementia patients typically fall into one of three categories:
 - Communication
 - Oral Intake
 - Cognition



Long Term Goal Examples

- Patient to recall and demonstrate safe use of cane to ambulate independently in facility and reduce fall risk
- Patient will recall and demonstrate safe bite size while eating to reduce choking risk
- Patient will recall facility room number to reduce wandering behaviors
- Patient will use memory book to locate and recall personal information/routines



Short Term Goal Examples

- Patient to recall reasons for needing cane at the beginning of 3 consecutive tx sessions using the Spaced Retrieval Technique to reduce fall risk
- Demonstrate use of smaller bite size while eating 80% of trials during meals with use of visual cue and minimal verbal cueing
- Correctly recall facility room number and locate room independently during 3 consecutive tx sessions using the Spaced Retrieval Technique.
- Read and utilize personal memory book to recall important personal information and daily routines 80% of trials with minimal verbal cueing



Document the Education!

- Caregiver demonstrated understanding of swallow precautions as evidenced by follow through with recommendations without the need for cueing
- Caregiver requires additional education regarding the importance of enforcing safe ambulation with assistive device by patient as she continues to keep the walker in the closet.





Part V: Understanding & Managing Behavior



- Ask "Why?"
 - "Why is this behavior occurring?"
- Brainstorm all possible reasons for behavior
 - Physiologic
 - Environmental
 - Lack of meaningful engagement
 - Personal (need for attention, social contact, reassurance, etc.)
- "Who Owns the Problem?"
- Ask person directly!



- Maximize remaining abilities to overcome challenges & develop appropriate interventions
- Find individual strengths for each resident and build on them
 - Observe resident
 - Ask family & staff
 - Provide opportunities
 - Engage in activities/Provide roles



- Coping Strategies:
 - Monitor the patient's personal comfort
 - Avoid confrontation
 - Respond to the emotion being conveyed, not the behavior
 - Allow rest between stimulating events
 - Try to not take behaviors personally

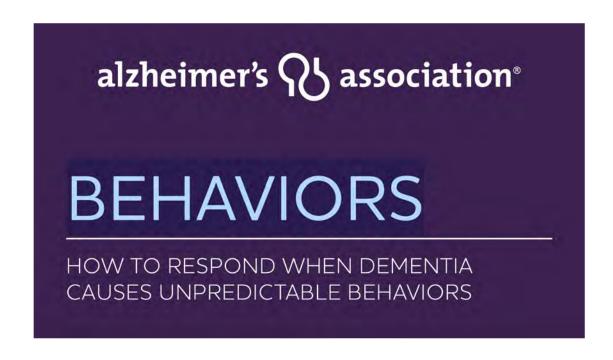
Alzheimer's Association, 2023 (7)



Repetitive Question Asking

- Ask Why?
- Brainstorm the possible answers
- Try some interventions!
- Expect that not everything will work initially
- Trial and error is okay.





Alzheimer's Association 2017 Behaviors Brochure:

https://www.alz.org/national/documents/brochure_behaviors.pdf



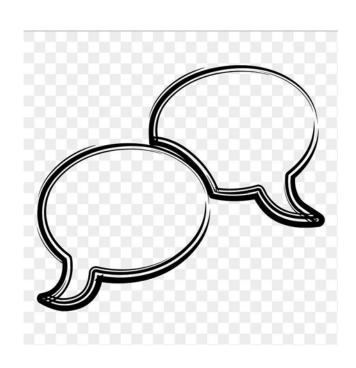
Part VI: Counseling, Educating & Supporting Families





For the Family

- Start immediately
- Give a little at a time
- Keep it simple
- Allow time
- Be realistic
- Encourage developing an Alternate Plan (Prepare for the future)
- Research and educate on local support groups





For the Patient

- Always try to include the patient in the conversation
- Never assume they don't understand
- Choose the appropriate time for discussion
- Grief needs to happen
- Don't force through the denial
- Choose battles wisely



5 Stages of Grief

- Denial: A coping mechanism that helps someone deal with the situation
- Anger: Can manifest itself in many ways. The caregiver may be the target of this anger.
- Bargaining: Family members may be looking for a cure or magic fix for the dementia.
- Depression: Increased overt expression of sadness
- Acceptance: Sometimes with acceptance comes a calm and relaxed relationship between loved ones.

(Kubler-Ross, 1969)



Part VII: Summary & Conclusion



The simple act of caring is heroic. - Edward Albert

Thank you for all you do and for joining us today!



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