



living with Alzheimer's

Learning objectives: Caregivers' Series, Late Stage

- Upon completion of this program, participants will be able to do the following:
 - Explain the concept of the self in the late stage of Alzheimer's disease.
 - Describe effective ways to communicate, connect with and provide daily care in the late stage.
 - List late stage care options and describe how to access and evaluate them.

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Late-stage symptoms

- The world is experienced through the senses.
- Impairment in memory increases.
- Language becomes more basic.
- Incontinence is typically an issue.
- Dependence on the caregiver increases.
- Physical abilities diminish.

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A new way of thinking about the late stage


- Traditional view of the late stage
 - Multiple losses
 - Focus on physical care management
 - Emotional life of the person not considered in formal care planning

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The person isn't lost to the disease



Mary O'Hara, LCSW, is a social worker at the Cognitive Neurology and Alzheimer's Disease Center at Northwestern University's Feinberg School of Medicine

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A new way of thinking about the late stage

- Holistic view of the late stage
 - Incorporates physical, emotional and spiritual aspects of care
 - Increases focus on the person's "self"
 - Individualizes care provision



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The "self" in a person with Alzheimer's



Sam Fazio, Ph.D., is Director of Special Projects, Medical and Scientific Relations, at the Alzheimer's Association's National Office.

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Changes in the caregiving role

- Personalities may shift in a different direction.
- Stories from long ago may emerge.
- Moments of clarity may occur.
- Lost abilities may reemerge through art or music.



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Changes in the caregiving role

- Changes are more pronounced.
- The care role becomes more physically demanding.
- Caregivers make all care decisions.
- Caregivers become the advocates for care.



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Caring for the caregiver



Mary Shore is Senior Director of Chapter Relations at the Alzheimer's Association's national office, and the daughter of a caregiver.

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Caring for the caregiver

- Taking care of yourself is a priority.
- Stress can be cumulative and may take its toll during the late stage.
- Surround yourself with support.
- Practice basic self-care.




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Communication changes



- Verbal messages shift to non-verbal cues.
- Try to learn what each cue means.
- Be in the moment with the person with the disease.

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Communication changes



Elizabeth Gould, LCSW, is Director of State Programs for the Alzheimer's Association's national office.

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Communication tips




- Communication without words
- Facial expressions
- Touch
- Sounds
- Body language

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How to spend time together



Martha Tierney, LCSW, is a Team Lead with the Helpline at the Alzheimer's Association's national office.

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Recognizing family and friends

- Identifying family and friends becomes difficult.
- Knowing that someone is important to him or her is common.
- The world is experienced through the senses.



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Intimacy



- Significant feelings of grief are normal.
- It is still possible to connect.
- Draw upon the power of touch.

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Meaningful activities

- Focus on remaining abilities.
- Incorporate music.
- Spend time outside.
- Modify activities.

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Meaningful activities



Melanie Chavin, is Vice President, Program Services at the Alzheimer's Association's Greater Illinois Chapter.

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Include the person in providing care

- Have the person imitate your actions.
- Guide his or her hand with yours.
- Talk through the process.
- Use the hand-over-hand technique.

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Daily care needs

- Around-the-clock care
- Decisions about long term care or additional services
- Close communication with doctors about marked changes
- Focus on quality of life and person-centered care



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Weight and eating changes



- Weight changes
- Swallowing difficulties
- Importance of working with physician and nutritionist
- Importance of changing expectations
- Fewer calories are needed
- Appetite and ability to taste will change

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Walking, sitting, and standing

- Physical changes affect the person's ability to move like he or she once did.
- Changes in gait and balance put the person at risk for falls.
- Using utensils, grasping, and holding objects become difficult.
- Sitting and smiling are affected in the late stage.

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Toileting issues

- The ability to know how and when to use the bathroom is impaired.
- The individual needs increasing amounts of assistance with toileting.
- Incontinence is a normal part of the late stage.
- Work with the doctor to ensure there are no other causes for the person's incontinence.

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Working with doctors

- Infections
- Weight, appetite, thirst
- Bowel and bladder changes



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Symptoms to report to doctors

- Fluid and electrolyte imbalance
 - Nausea, cramping, muscle spasms and lightheadedness
- Pneumonia
 - Cough, fever, lightheadedness, teeth-chattering, fatigue and diarrhea.
- Urinary tract infections (UTIs)
 - Sudden increased confusion or shifts in personality and/or behavior.

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Symptoms to report to doctors

- Bed sores or pressure sores
 - Red spots, particularly in bony areas, which develop into ulcerated skin with blisters or craters.
 - Prolonged pressure or friction from moving
 - Ageing skin
 - Lack of ability to sense pain or the need to change positions
 - Weight loss
 - Poor nutrition and hydration
 - Urinary or fecal incontinence
 - Excess moisture or dryness of the skin
 - Medical conditions affecting circulation

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Symptoms to report to doctors

- Bed sores or pressure sores
 - Red spots, particularly in bony areas, which develop into ulcerated skin with blisters or craters
- Behavioral symptoms
 - Hallucinations
 - Seeing or sensing things that are not there
 - Delusions
 - Believing things that are not real
 - Agitation or aggression

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Late-stage medications

- Cholinesterase inhibitors
 - Donepezil (Aricept)
 - Now approved for all degrees of Alzheimer's (mild, moderate and severe).
- N-methyl-D-aspartate (NMDA) receptor antagonist
 - Memantine (Namenda)
 - Approved for moderate to severe Alzheimer's.
- Combination medication
 - Namzaric (Combines Namenda and Aricept into one extended release capsule)
 - Released in 2014 for moderate to severe Alzheimer's in people who are already stable on Namenda and Aricept.

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Medications for difficult symptoms



Ron Petersen, MD, PhD, is Director of the Mayo Clinic's Alzheimer's Disease Research Center.

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Monitoring care

- Mobility problems
- Rigidity
- Restlessness
- Changes in sleep patterns
- Breathing difficulties



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Pain management

- Challenges in late stages:
 - Pain assessment
 - Pain management
- Team approach to evaluation and management of pain includes:
 - Caregiver
 - Medical care team

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Keeping the person healthy

- Moisturize the skin.
- Learn to lift.
- Maintain range of motion.
- Keep the person moving.
- Clean and treat vulnerable areas.
- Get flu vaccines.
- Talk with the person's doctor about dramatic changes in functioning.

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Crisis preparation




- Communicate with care partners.
- Know who to call in the event of a crisis.
- Understand DNR orders

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Family choices




- Choices regarding treatment may need to be made using:
 - Advance directives if these are in place, or
 - Guardianship arrangements that now must be made through the court.

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You can't do this alone anymore




Kitty's husband, Bill, has a diagnosis of Alzheimer's disease.

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Summary

- Maintenance of the sense of self
- Communication
- Physical care
- Self-care for the caregiver



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