



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.

2 alzheimer's association



living with Alzheimer's

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.

4 alzheimer's association

living with Alzheimer's


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

5 alzheimer's association

living with Alzheimer's

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

6 alzheimer's association

living with Alzheimer's

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



7 alzheimer's association

living with Alzheimer's

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.

8 alzheimer's association

living with Alzheimer's

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.




9 alzheimer's association

living with Alzheimer's
complicated

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.



10 alzheimer's association

living with Alzheimer's
complicated

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.

11 alzheimer's association

living with Alzheimer's
complicated

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.



12 alzheimer's association

living with Alzheimer's

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.

13 alzheimer's association

living with Alzheimer's

Communication changes



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

14 alzheimer's association

living with Alzheimer's

Communication tips



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

15 alzheimer's association

living with Alzheimer's

How to spend time together



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

16 

living with Alzheimer's

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.



17 

living with Alzheimer's

Intimacy



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

18 

living with Alzheimer's
complicated

Meaningful activities

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

19 alzheimer's association

living with Alzheimer's
complicated

Meaningful activities



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

20 alzheimer's association

living with Alzheimer's
complicated

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.

21 alzheimer's association

living with Alzheimer's

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



22 alzheimer's association

living with Alzheimer's

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

23 alzheimer's association

living with Alzheimer's

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.

24 alzheimer's association

living with Alzheimer's

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.

26 alzheimer's association

living with Alzheimer's

Working with doctors

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



26 alzheimer's association

living with Alzheimer's

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.

27 alzheimer's association

living with Alzheimer's

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

28 alzheimer's association

living with Alzheimer's

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

29 alzheimer's association

living with Alzheimer's

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.

30 alzheimer's association

living with Alzheimer's

Medications for difficult symptoms




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

31 alzheimer's association

living with Alzheimer's

Monitoring care

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



32 alzheimer's association

living with Alzheimer's

Pain management

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

33 alzheimer's association

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.

34

Crisis preparation



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

35

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.


36

living with Alzheimer's
compared

You can't do this alone anymore




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

37 

living with Alzheimer's
compared

Summary

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



38 