

Alzheimer's Disease: Late-Stage Care

2.0 Contact Hours

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Alzheimer's Disease: Late-Stage Care

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Objectives:

At the completion of this course, the learner will be able to:

1. Identify the symptoms associated with late-stage Alzheimer's disease.
2. Describe five strategies for addressing nutritional challenges and bowel and bladder issues during late-stage Alzheimer's disease.
3. Explain how to enhance health in light of the immobility, increased risk for illness, and difficulty communicating pain that are characteristic of late-stage Alzheimer's disease.
4. Name at least three ways to provide comfort to a person with late-stage Alzheimer's disease by nurturing a personal connection with the individual.
5. List two kinds of decisions that caregivers and families often need to make during late-stage Alzheimer's disease.

Introduction

When Alzheimer's disease is discussed in educational or public forums, the early and middle stages often receive the most attention. The early stage encompasses the warning signs that first indicate a person might be experiencing cognitive impairment, while the middle stage is characterized by disturbing behaviors such as wandering, suspicion, repetition, and sometimes agitation or aggression. When Alzheimer's is represented in fictional stories, these are the stages most often depicted.

However, there is a late stage of Alzheimer's disease that is rarely discussed, yet it is vitally important that those in the late stage receive just as much attention and care as those in earlier stages. This course is designed to help health care professionals understand what happens to individuals during late-stage Alzheimer's disease. Late-stage

symptoms will be described, followed by a discussion of strategies to help those in the late stage acquire proper nutrition and achieve optimal bowel and bladder function. Approaches will also be explained that address the immobility, increased risk for illness, and difficulty communicating pain that are characteristic of late-stage Alzheimer's.

Next, strategies for providing comfort will be delineated, with a focus on forging a personal connection with individuals in the late stage of Alzheimer's disease. Finally, because health care professionals work with caregivers and families as well as patients, decisions that families often need to make when a relative enters late-stage Alzheimer's disease will be clarified so that professionals can respond appropriately during these difficult situations.

Symptoms of Late-Stage Alzheimer's Disease

In the earlier stages of Alzheimer's, the disease affects cognitive processes (e.g., thinking, memory, orientation, judgment) and behavior more than physical functioning. In late-stage Alzheimer's, the disease finally begins significantly affecting parts of the brain that control bodily systems such as motor coordination, bowel and bladder function, and even breathing. The late stage of Alzheimer's disease usually requires rigorous, around-the-clock care; the stage can last from several weeks to several years. The symptoms of late-stage Alzheimer's disease often include:

- Increased vulnerability to infections, such as pneumonia and the flu
- Difficulty walking and moving – eventually, the person becomes chair-bound or bed-bound
- Loss of the ability to communicate through words
- Difficulty swallowing and eating

- Total incontinence of bowel and bladder, requiring full-time assistance with toileting and hygiene
- Eventual inability to sit up or hold up one's head
- Loss of facial expressions, including the ability to smile

Individuals with Alzheimer's disease often die of a medical complication such as pneumonia or the flu. However, although not often recognized as such, Alzheimer's is fatal – if there are no other complications, the person will die when all bodily systems fail because of the disease.

Enhancing Nutrition in Late-Stage Alzheimer's Disease

While everyone requires adequate nutrients and hydration in order to maintain health, those with late-stage Alzheimer's disease are at particularly high risk for malnutrition because of problems with eating and swallowing. Additionally, swallowing difficulties can cause an individual to breathe liquids or food particles into the airway and lungs. This puts the person at an increased risk for developing pneumonia. The following strategies can help those with late-stage Alzheimer's eat and drink in a safe manner:

- *Create a calm, quiet eating environment.* While it might be tempting to turn on the television while assisting patients with feeding, noise from the television, radio, or other sources can be distracting for the person with late-stage Alzheimer's. Have the person eat in a calm, quiet place, using a simple table setting if the person can still use utensils.
- *Make sure the individual is comfortably seated.* The person should be seated upright while eating and should remain upright for at least a half hour after eating in order to aid digestion.

- *Be patient and adaptable.* Eating will take longer during the late stage of Alzheimer's disease. While time is precious for health care workers, try to allow the person ample time for meals. Over time, adjustments might be necessary in order to accommodate changes in food preference or portion tolerability. Individuals with late-stage Alzheimer's sometimes eat more if they are offered smaller meals or snacks throughout the day rather than three larger meals.
- *Choose easy-to-swallow foods.* Provide soft foods that can be easily chewed and swallowed. Bite-sized foods also work well, as do finger foods such as cheese cubes or mini-muffins. If the person can no longer eat solid food, try mashing up the food or pureeing it in a blender.
- *Encourage fluid consumption.* Alzheimer's disease sometimes impedes a person's ability to realize he or she is thirsty, so it is important to provide frequent opportunities to drink liquids. If swallowing water is problematic, try offering fruit or vegetable juice, soup, yogurt, or flavored ices. Liquids can also be thickened by adding cornstarch or unflavored gelatin.
- *Be prepared for choking incidents.* Because late-stage Alzheimer's often includes problems with swallowing, coughing and choking are serious risks during meals. Be sure that all staff can perform the Heimlich maneuver and are prepared for choking emergencies.
- *Encourage, then assist.* Even in the late stage of Alzheimer's, some individuals can still feed themselves to some degree when provided cues and encouragement. Guiding the person through the first bite may initiate self-feeding. If it is clear that the person cannot feed himself or herself, offer food and beverages slowly,

making sure that everything is swallowed before offering the next bite or drink.

Reminders to chew and/or swallow can move the process along.

Improving Bowel and Bladder Function in Late-Stage Alzheimer's Disease

If you notice problems or changes in bowel and bladder function, be sure to rule out any acute medical problems – for example, fecal impaction or a urinary tract infection – before assuming that the problems are simply due to late-stage Alzheimer's. To improve bowel and bladder function, try the following strategies:

- *Eliminate caffeinated beverages.* Liquids that contain caffeine, such as coffee, tea, and some carbonated beverages tend to aggravate urinary incontinence because caffeine increases the flow of urine.
- *Reduce liquid consumption in the evening.* While it is important to keep late-stage Alzheimer's patients hydrated, try to reduce liquid consumption during the two hours before bedtime in order to reduce incidents of incontinence during the night.
- *Use protective briefs and absorbent bed pads.* Briefs and pads are effective tools for handling incidents of incontinence, even when other strategies work most of the time.
- *Watch for constipation.* While it is not imperative that the person has a bowel movement every day, it should be noted if the individual goes three or more days without having a bowel movement. Besides checking for fecal impaction, adding natural laxatives to the person's diet can help (e.g., high-fiber snacks like prunes).
- *Follow a toileting schedule.* Individuals with late-stage Alzheimer's should be taken to the bathroom or given a bed pan every couple of hours. Keep a written

chart documenting when the person successfully goes to the bathroom as well as when and how much the person eats and drinks. Tailor the toileting schedule to the individual's unique toileting routine.

Addressing Immobility in Late-Stage Alzheimer's Disease

In late-stage Alzheimer's disease, becoming chair-bound or bed-bound poses serious risks to the person's body, skin, and overall health. For example, joints may "freeze," pressure sores may develop, and the skin may break down or become more vulnerable to tears and bruises. Try the following methods to address immobility in late-stage Alzheimer's disease:

- *Apply range-of-motion exercises.* When a person is confined to a bed or chair for long periods, limb contractures can occur, which are also called "frozen" joints. To reduce a person's risk of contractures, have a physical therapist or other staff member trained in range-of-motion exercises perform a sequence of arm and leg movements with the individual two or three times a day. It is best to perform range-of-motion exercises when a person's muscles are warm, such as directly after bathing.
- *Keep skin dry and clean.* In late-stage Alzheimer's, the skin becomes more fragile and susceptible to bruises and tears. Check the person daily for evidence of sores, rashes, or other problems. When bathing the person or providing other help with hygiene, wipe the skin gently and avoid any harsh friction with washcloths or other abrasive materials. Be sure to dry the skin completely after washing.

- *Reposition every two hours.* Changing an individual's position every two hours can relieve pressure on certain areas of the body and reduce the incidence of pressure sores. When repositioning, always ensure that the person is comfortable and in proper alignment. Pillows can be used to support the person's head, arms, and legs, as well as to protect bony areas such as knees and elbows. Make sure that staff members are trained in proper lifting and turning procedures.

Reducing the Risk for Illness in Late-Stage Alzheimer's

In addition to skin and joint problems, immobility in late-stage Alzheimer's weakens the immune system, making one more vulnerable to illness. To reduce the risk for infections and other illnesses in late-stage Alzheimer's, take the following precautions:

- *Provide immediate treatment to cuts and scrapes.* Basic first aid can go a long way toward preventing infections in those with late-stage Alzheimer's disease.
- *Practice consistent oral hygiene.* Those with optimal oral health have a reduced risk of developing bacteria in the mouth that can cause infection. Regular tooth brushing or denture cleaning is paramount. It also helps to clean the soft tissues of the mouth using moistened gauze pads or a soft toothbrush in order to prevent inflammation of the gums (i.e., gingivitis).
- *Vaccinate when appropriate.* Unless there are contraindications due to allergies, be sure that all staff members and patients have flu shots every year. A vaccine for pneumonia is also available and should be administered every five years.

Recognizing Pain in Late-Stage Alzheimer's Disease

While it is important to keep individuals comfortable during late-stage Alzheimer's, this can be challenging because the disease affects communication in such a way that it is harder for those in pain to indicate that they are uncomfortable. There are three ways to recognize pain in late-stage Alzheimer's disease:

- *Physical indicators.* If a patient with late-stage Alzheimer's is showing physical symptoms such as dry or pale gums, sores in the mouth, pale or flushed skin, vomiting, or swelling of any body part, there is a good chance that illness and/or an infection are present, making the patient uncomfortable.
- *Behavioral indicators.* Individuals with late-stage Alzheimer's may show sudden changes in behavior when they are in pain, such as agitation, combativeness, or insomnia.
- *Nonverbal communication.* Even though individuals in late-stage Alzheimer's cannot communicate effectively through words, they may still indicate that they are in pain through their facial expressions (e.g., grimaces), gestures (e.g., pointing to a body part), or vocal sounds (e.g., groaning).

Providing Comfort through a Personal Connection with the Person with Late-Stage Alzheimer's Disease

When late-stage Alzheimer's reduces a person's ability to communicate through words, it can seem futile to try to make a connection with the person. However, those with late-stage Alzheimer's can still experience the world through senses such as touch, smell, sound, and sight. It is essential to continue providing comfort to those with late-

stage Alzheimer's disease by nurturing a personal connection with them through the following methods:

- *Tap into the person's senses.* Learn about the person's history to generate ideas for tapping into the person's senses. Was the individual a gardener? Perhaps she would enjoy the smell of fresh cut flowers or herbs. Does the person love animals? He might find pleasure in stroking a dog or cat that is appropriate for patient visits. Those who enjoy the outdoors might enjoy bird watching. Music that represents an enjoyable time in the person's life or an ethnic or spiritual tradition can be a comforting way to communicate through sound. The key is to find a way to tap into the senses of the individual by paying attention to the person's unique qualities.
- *Use touch.* Simply holding a person's hand or providing a gentle massage can communicate reassurance and caring to a person with late-stage Alzheimer's.
- *Speak in a soothing tone.* Even if the person with late-stage Alzheimer's can no longer understand what you are saying, speaking in a gentle, soothing tone of voice can provide comfort and a feeling of safety. Similarly, the rhythm of reading to the person can be relaxing, even if the individual does not understand what you are reading.

Providing Support and Information to Caregivers and Families

When an individual enters the late stage of Alzheimer's disease, the person's primary caregiver – often a spouse or adult child – and other family members are faced with some difficult decisions. Keep in mind that there often are no clear-cut answers to many of these decisions, but as a health care professional, you can assist family members

by providing support and information about late-stage Alzheimer's disease and end-of-life resources. Some of the issues families may raise include:

- *The benefit of medications.* While some medications can be useful in the early or middle stages of Alzheimer's, their benefit is questionable in the late stage of the disease. Families may wonder whether they are prolonging their relative's suffering by keeping them on an Alzheimer's medication or drugs for concurrent conditions.
- *What services to use.* It is difficult for caregivers and families to keep their loved ones at home during the late stage of Alzheimer's disease without outside help. However, families may not understand all of the options available to them, including home health care, nursing home care, hospice care, and palliative care.
- *Legal aspects of end-of-life decisions.* Family members might not be prepared for decisions about feeding tubes, resuscitation, and other interventions if they do not understand the procedures or know their loved one's wishes.

Conclusion

A person in late-stage Alzheimer's disease faces serious risks such as malnutrition, bowel and bladder problems, immobility, infection and illness, pain, and communication challenges. As a health care professional, you can take concrete steps toward addressing these issues while nurturing a meaningful, personal connection with those in the late stage of Alzheimer's. You can also help caregivers and family members in their decision making by providing support and information about late-stage Alzheimer's and the issues that accompany this difficult disease.

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