

Late Stage Alzheimer's - Tips for Caregivers

A person in the late stage of Alzheimer's disease is less able to communicate needs and wishes. Around-the clock assistance is required, and compassion and respect are key.

What to Expect in the Late Stage:

- ♦ Difficulty walking and communicating.
- ♦ Surroundings may seem unfamiliar because the past is confused with the present.
- ♦ Wandering out of familiar areas may occur and may become worse after sunset.
- ♦ Incontinence of bladder and/or bowel.
- ♦ Sensitivity to food textures.
- ♦ Inability to recognize hunger.
- ♦ Difficulty swallowing.
- ♦ Weight loss, even with a good diet.
- ♦ May put inappropriate objects in mouth.
- ♦ May see or hear things that are not there.
- ♦ May have periods when their facial expression is blank.
- ♦ May sleep more.
- ♦ Can still benefit from touch and attention.

Caregiver Tips and Strategies:

- ♦ Read to your loved one.
- ♦ Make or review a scrapbook or photo album.
- ♦ Play or sing music from your loved one's era.
- ♦ Touch is comforting. Stroke the individual's hand or brush her hair.
- ♦ Be aware of signs of pain and discomfort.

Informed Caregiving:

- ♦ Consider what the goals of care and treatment are in the late stage of Alzheimer's disease.
- ♦ If the person with Alzheimer's composed a living will or advance directive, distribute it to family members and all healthcare providers so everyone understands what your loved one planned.
- ♦ If a living will or advance directive has not been completed, talk to the doctor and understand the facts about life-sustaining treatment options, including feeding tubes and intravenous hydration.
- ♦ Comfort care (also known as palliative care) focuses on quality of life rather than prolonging life. Hospice programs provide comfort care to individuals in the final stages of life.
- ♦ Make informed decisions by:
 - ♦ Focusing on the individual's wishes.
 - ♦ Weighing the pros and cons of each treatment.
 - ♦ Considering the location for care.
 - ♦ Considering the prognosis and quality of life issues.
 - ♦ Reflecting on the individual's values.
 - ♦ Involving an objective third party (e.g clergy or attorney) to resolve family conflicts.

Communication in the Late Stage of Alzheimer's Disease

After the ability to use words and language is lost, the person with Alzheimer's experiences the world through their senses — sight, hearing, taste, touch, and smell. You can communicate love and reassurance by giving a gentle hand massage with scented lotion, or by playing music that the person loves. Even if the person no longer understands the content of your words, he/she can be comforted by the tone of your voice.

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End of Life Terms to Know:

Advance Care Planning: a decision-making process that families can use to decide best options for future care, including possible residential facilities, legal and financial issues, and what medical treatments might be used at different points in the disease. Ideally, advance care planning occurs early in the disease, when the person still has legal capacity to make decisions about future care.

Advance Directives: legal documents that indicate what kinds of medical care the individual would like to receive in certain situations, if he/she is no longer able to make medical decisions. Also appoints someone who will serve as Durable Power of Attorney for Health Care.

Capacity: a term that describes a person's ability to understand consequences of making certain medical and financial decisions, and his/her ability to communicate decisions.

Do Not Resuscitate order (DNR): is a physician's medical order, based on their patient's (or their durable power or attorney for healthcare's) wishes, to withhold life-sustaining treatment such as cardiopulmonary resuscitation if the heart stops.

Durable Power of Attorney for Healthcare: is a document that designates a healthcare proxy to make healthcare decisions for the person who no longer has capacity.

Hospice Care: comfort or palliative care that is provided at home or in a facility. Hospice care is typically for people who have a life expectancy of six months or less.

Palliative Care: Also known as comfort care, refers to care that focuses on maximizing quality of life rather than extending life.

Practitioner Orders for Life Sustaining Treatment (POLST)

Signed into legislation in New Jersey in 2011, a POLST is a form signed by a patient's attending physician or advanced practice nurse. It provides instructions for healthcare personnel to follow for a range of life-prolonging interventions and emphasizes the patient's goals of care and medical preferences. This form becomes part of a patient's medical records, following the patient from one healthcare setting to another, including hospital, home, nursing home, or hospice. It does not replace an advance directive; it is a complementary document that serves as a medical order that must be followed. To learn more, ask your healthcare provider.

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