

Preparing for the Late Stage

Learning what to expect in the later stage of Alzheimer's disease is as important as preparing yourself to provide care at any other stage of the disease. During the late stage of the disease there are different aspects of care that you will be called upon to provide. In this overview, we will outline what you may notice if someone is in the late-stage of the disease, what decisions will need to be made and what resources are available for support.

How do I know if the person is in late stage?

An individual in the late stage will experience changes in; memory and thinking, communication, mood and behavior, and physical needs.

The person will likely experience changes to memory and thinking in the following ways:

- Experience increased difficulty remembering long-term memories
- Difficulty recognizing the most familiar people
- Not able to tell the most well-rehearsed story or memory
- Greater impact to short-term memory

Strength: The person is able to experience and be engaged in each moment

The person will likely experience changes in communication in the following ways:

- Difficulty carrying on a conversation
- Challenge interpreting what is being said by you
- Labored verbal expression of needs and feelings

Strength: The person is perceptive and is in-tune to emotion, tone and feeling.

Communication occurs but is more non-verbal. Using humor is one positive way to connect with the person; don't be afraid to be silly or laugh

The person will likely experience changes in mood and behavior in the following ways:

- Harder to be present in an activity or event, appears withdrawn or dis-interested
- Difficulty being involved in everyday activities in the traditional sense
- Sleeping more than they are awake

Strength: The person experiences a wide range of emotions from joy/sadness to pride/embarrassment. You can meet the person's needs and bring comfort by using the person's personal comforts and or addressing unmet needs

The individual will likely experience changes in physical function in the following ways:

- Need total assistance in personal care, dressing, grooming, bathing and eating
- Decreased ability in fine-motor skills
- Difficulty walking, experiencing loss of coordination and balance
- Require 24-Hour Supervision

Strength: The person has a desire to be engaged and included, finding ways to modify every-day activities to more accessible. You can bring comfort to the person by noticing their physical need for movement or adjustment

Identifying unmet needs

Verbal communication is not reliable when the person is in the late stage of the disease. For the care-partner it is important to identify what needs the person has that they may no longer be able to express, such as:

- Is the person experiencing hunger and/or thirst? Providing the person with food and drink rather than expecting them to say or initiate eating/drinking
- How is the person's wake/sleep cycle? Providing flexibility around daily routines to meet the varied times of day the person is awake or asleep, meet them where they are
- Do they need to alleviate bowel or urination? The person may be experiencing constipation and/or want to use the toilet to do so
- Do they need to have movement and motion? If the person is not able to easily move their body without assistance they may experience aches and pains from lack of movement-adjust the person's weight using pillows, recliners, gel pad mattresses to increase comfort
- Are they experiencing changes in bodily temperature? Checking in on the person to ensure they are comfortable, removing clothing or adding extra blankets

Using the five senses to connect

A person in the late stage of Alzheimer's disease will be less verbally communicative but will likely retain their ability to experience their environment and maintain connections through their other senses. Consider these strategies to engage the person:

- **Sight**- Dim the lights, pictures of loved ones, nature images, favorite places/vacations
- **Smell**- Essential oils, freshly washed laundry, a favorite food being cooked/baked
- **Taste**- More likely to want salty/sweet foods, what do they crave?
- **Sound**- Music they love, sounds of nature, sounds of the kids, family pet
- **Touch**- A firm hand on the persons shoulder or knee, a weighted blanket, warm socks

Important Health Care Decisions

There are many decisions to make at this time and it is important to consider the person's quality of life. For example, if an intervention or treatment is proposed by the doctor or medical team consider whether this will cause more pain/discomfort or will it bring greater quality of life. Thinking about these interventions and where you and/or the person stand on these issues will allow you to make a more-informed decision in the person's interest. Issues include;

- CPR
- Feeding tube
- Intravenous hydration
- Use of antibiotics
- Surgery

Available Resources

Alzheimer's San Diego

We are here to support you talking through decisions, options and processing normal grief reactions. Connect with one of our Social Workers today by calling 858-492-4400

Hospice Care

Hospice services are available to anyone and are often covered by Medicare. Hospice services help people at the end of life be comfortable, and minimize the experience of pain; its focus is not to re-habilitate, or get someone back to where they were, but rather to allow the natural process of dying. Hospice is more than just specialized medical care at the end-of-life it is a source of support for the entire family

For more information talk to your doctor, and check out these resources for more information:

- National Hospice & Palliative Care Organization <https://www.nhpco.org/find-hospice>
- California Hospice & Palliative Care Association <http://calhospice.org/>

Palliative Care

Palliative care is similar to hospice in that its goal is to help the person experience a high quality of life, but unlike hospice, it is not only for those at end-of-life, and uses life-sustaining treatments. The National Institute of Health explains; “Interdisciplinary palliative care teams assess and treat symptoms, support decision making and help match treatments to informed patient and family goals, mobilize practical aid for patients and their family caregivers, identify community resources to ensure a safe and secure living environment, and promote collaborative and seamless models of care across a range of care settings, (i.e., hospital, home, and nursing home)” (Meier, 2011)

Each has their own philosophy of care and interventions to connect with the individual i.e. music therapy, aromatherapy, massage. Other sources of support during this time include geriatric care managers, and grief counselors

Improving Quality and Honoring Individual Preferences Near the End of Life. Washington (DC): National Academies Press (US); 2015 Mar 19. 2, The Delivery of Person-Centered, Family-Oriented End-of-Life Care. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK285676/>

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