

- to authorize surgery to place a tube into the stomach for artificial nutrition (food) or artificial hydration (water), or
5. whether to use restraints to keep the person from removing the tubes.

A big decision you will be asked about is what doctors and nurses should do when your loved one's heart or breathing stops. Unlike what we see on TV, very few people with end stage illnesses survive by others restarting their heart or lungs (resuscitation).

Remembering what mattered most during the healthy years will help guide medical decision-making. For example, think about times your loved one talked about the possibility of illness. What desires did you hear expressed? How important was comfort? Was living longer (quantity) more important than quality of life?

### References

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### Get Support and Information

The Laguna Honda care team will provide information, recommend treatment, clarify goals of care, and support you in this process. Please ask for help.

### Additional Resources

Alzheimer's Association  
<http://www.alz.org/>

American Geriatrics Society  
[http://www.americangeriatrics.org/files/documents/Adv\\_Resources/AGS.Statement.On.Advance.Care.Planning.01.2011.pdf](http://www.americangeriatrics.org/files/documents/Adv_Resources/AGS.Statement.On.Advance.Care.Planning.01.2011.pdf)

Coalition for Compassionate Care of California  
<http://www.coalitionccc.org/advance-health-planning.php>

Family Caregiver Alliance  
<http://www.caregiver.org/caregiver/jsp/home.jsp>

National Institutes of Health  
<http://www.ninds.nih.gov/disorders/dementias/dementia.htm>

Laguna Honda Hospital and Rehabilitation Center, a branch of the San Francisco Department of Public Health, is a 5-star skilled nursing facility providing acute care, skilled nursing and rehabilitation services to a safety net population of 768 seniors and adults with disabilities.



415-759-2300  
[www.lagunahonda.org](http://www.lagunahonda.org)

## What to Expect As Alzheimer's Dementia Progresses To End Stage



 **LAGUNA HONDA**  
HOSPITAL AND REHABILITATION CENTER  
SAN FRANCISCO DEPARTMENT OF PUBLIC HEALTH

## Introduction

Dementia is a general term for decline in mental ability severe enough to interfere with daily life (www.alz.org). Alzheimer's dementia and stroke-related dementia (vascular) are the most common types of dementia. There is no cure for Alzheimer's dementia. There are some medications that may slow the progression and help with symptoms. However, Alzheimer's dementia eventually progresses or worsens, leading to complications that cause death.

### What happens as Alzheimer's dementia progresses to the end stage?

As dementia worsens, people are able to do less and less for themselves. Those who once were only slightly forgetful lose the ability to do basic things. They forget parts of their past or sometimes all of it. Eventually, they may not recognize loved ones. The change can be very painful for family and friends.

People with end-stage dementia no longer remember how to talk, move, walk, use the toilet, eat or engage in other daily activities. They may develop behavior problems and no longer act like themselves. Because they may not move much, and may have bowel or bladder accidents, they may develop bedsores (pressure ulcers).

### Common Medical Problems

Several medical problems develop as dementia progresses, including infections and problems with eating, drinking and swallowing.

#### 1. Infections & Fevers

Fevers and infections may occur in advanced dementia. Infections can happen in the lungs (pneumonia), the bladder, or the kidney (urinary tract infections). Almost half of people who have dementia will get pneumonia at least one time. Repeated infections are also common. These infections are not always preventable, and may not get better with antibiotics.

#### 2. Eating & Drinking Difficulties

As dementia reaches the end stage, eating and drinking difficulties occur in almost all people. They will forget or refuse to eat or drink. They may even lose all interest in eating and drinking. Though refusing nourishment is normal at the end of life, watching a loved one who no longer finds pleasure in eating or drinking is very difficult.

#### 3. Swallowing Problems

Some people hold food in their mouth, or let the food spill out, even when they are assisted by their caregivers. Though a person may appear to be swallowing, it is possible that food, liquid, or even their spit (saliva) may go down the wrong way and enter into the lungs. This can cause a lung infection called aspiration pneumonia.

Aspiration may not be preventable, even with pureed or soft foods or other special ways to help with feeding. There is no scientific evidence to show that artificial nutrition through a tube in the nose or stomach prevents aspiration pneumonia, improves quality of life, or offers comfort. Tubes in the nose or stomach can be bothersome and

persons with advanced dementia may try to pull them out. In such a case, restraints such as mittens, belts, and abdominal binders may need to be used.

For persons with advanced dementia, artificial nutrition may result in serious problems. Complications, such as pneumonia, bleeding, or infections where the tube enters the body, may require transfer to the emergency room, or to the hospital. Going to an emergency room or hospital in an ambulance may be scary for some people with dementia.

### Decision Difficulty

People with advanced dementia have difficulty making medical decisions for themselves. As a result, family and friends are asked to speak for the person, and to help guide decision-making based on what their loved one felt was important. Deciding for someone else is stressful; knowing the person's wishes in advance, through an advance directive, helps.

### What decisions might you be asked to help the doctor with?

Some decisions include

1. whether to use medicines to quiet or calm the person,
2. whether to keep treating infections with antibiotics (sometimes this means shots or injections),
3. whether to transfer your loved one to the emergency room or hospital for more aggressive medical treatments,
4. whether to place a tube into the nose or