

## Nutrition and Hydration – Client and Family

This pamphlet answers commonly asked questions about the changing nutrition and hydration needs of residents who are living in aged care facilities at the end of life. Related pamphlets cover the topics of *Transfers Between Care Settings* and *Medication Management* at the end of life.



### Nutrition and hydration at the end of life

As people near the end of life, they often experience a decrease in appetite. People may lose their interest in food and drink, experience chewing or swallowing difficulties or may be unable to digest food.

While a decrease in appetite and thirst is an expected part of dying, it can be difficult watching someone experience this and you may feel worried they will starve or become dehydrated.

It is natural for families and carers to try to convince or help their loved ones to eat or drink, but it is important to understand that this can cause unnecessary pain and suffering in a person's last days.

### Why have they stopped eating and drinking?

As a person nears death, their body and vital organs slow down and will eventually stop working. At this point, the body does not need food or drink. People typically won't experience thirst or hunger and won't be interested in eating or drinking.

Health professionals and care staff at the aged care facility will continue to offer people food and drink in different ways to suit their changing needs and preferences, until they no longer want it.



### **Is someone close to dying when they stop eating or drinking?**

It is difficult to say how long it will be before a person dies once they stop eating or drinking.

For some people, death will occur within days; for others it may be weeks after they stop eating and drinking. For most people, death will occur within 10 days after they stop eating or drinking.

Health professionals and care staff at the aged care facility will continue to monitor and assess people as they are dying to ensure that supports are given according to their needs and preferences.

### **Are they starving?**

No. A person in the palliative phase is not dying because they are not eating. They have stopped eating because they are dying.

While it is normal to be worried that people are starving, it is equally important to remember that starving usually refers to someone who wants food and would eat if they could. A person who has stopped eating and drinking by choice has begun the natural process of dying and in these circumstances, the person rarely feels hungry and sometimes even the smell or thought of food may be nauseating to them.



### **If a person refuses to eat or drink should a feeding tube or intravenous fluids be started?**

While one of the most basic human instincts is to provide nourishment for ourselves and for others, it is important to remember that the goal of end of life care is to provide comfort and relieve uncomfortable or distressing symptoms.

Giving food and fluids through a vein or through a feeding tube does not prolong life or improve its quality for people who are dying. In fact, doing this may cause discomfort or increase distressing symptoms such as shortness of breath, respiratory congestion, restlessness, nausea and vomiting.

Health professionals and care staff will comprehensively assess a person's needs as they near the end of their life to determine the supports needed.

### **What if someone wants to eat or drink but is having trouble swallowing?**

It is important that a person's choices and preferences are always respected. If a person has capacity and can understand the risks, it is their right to decide whether or not to continue to eat or drink, even if they are experiencing difficulties swallowing.

### **Who decides when it is time to stop feeding a resident who is dying?**

Health professionals at the aged care facility will involve the person (or substitute-decision maker if they do not have capacity in making decisions) and follow their preferences. If the person wishes, their family or friends may also be part of discussions about eating and drinking at the end of life.

There may be a family meeting (sometimes called a case conference) to enable the person, their family or friends, and key health professionals and care staff to communicate, plan care and make decisions relating to end of life in accordance with the person's wishes.

The person may have an Advance Care Directive which records their choices about treatment options. It may include a refusal to receive artificial nutrition and hydration. This needs to be respected.

Health professionals and care staff may also connect with other health professionals who will form part of the person's care team. This team will work together with the person and their support network to provide integrated palliative care.

### **Conversations about the end of life**

Having conversations about death and dying with the person and the health professionals and workers who care for them can be an important way to prepare for their death.

While these conversations can be difficult, they can enable you to understand the person's wishes and how you can be involved in their end of life care.



### Key actions the residential aged care facility will take to support a resident's nutrition and hydration needs at end of life

- Regularly assess and respond to the person's changing nutrition and hydration needs and preferences
- Seek expert input (e.g., from a dietitian or speech therapist) where needed
- Understand and support (as best as possible) what, how, when and with whom the person wants to eat and drink
- Enable the person to make informed choices and take risks (e.g., continuing to eat when there are swallowing risks or refusing the use of artificial nutrition and hydration supports)
- Follow relevant directions in the person's Advance Care Directive
- Involve the person's substitute decision-maker if they do not have the capacity to consent or make choices
- Communicate with and involve family or friends in discussions and care planning, if the person wants.

The Aged Care Quality Standards require that *'The needs, goals and preferences of consumers nearing the end of life are recognised and addressed, their comfort maximised and dignity preserved.'* (Standard 3(3c))

### Helpful resources

- Aged Care Quality & Safety Commission resources on [Food and Dining](#) including [Enjoying Dining in Aged Care](#)
- ELDAC's [End of Life Law Toolkit](#)
- Aged Care Quality Standards [consumer resources](#)
- [Charter of Aged Care Rights](#)

This resource has been informed by a review of contemporary Australian and international literature including authoritative sources on the Australian policy, legal and practice environment. Additionally, three focus groups of nurses working in a variety of aged care settings were held and content was reviewed by experts in the ELDAC network.