ELDAC
End of Life Directions for Aged Care

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.

Medications – Client and Family

This pamphlet includes information about medications that may be given to people who are dying to increase their comfort and relieve suffering. Related pamphlets cover the topics of *Transfers Between Care Settings* and *Nutrition and Hydration* at the end of life.

Medications at the end of life

As people near end of life, the goals of their care change from trying to improve or maintain their health to maximising their comfort and quality of life in their final days.

An important part of making sure someone nearing end of life is comfortable is to provide medication that will relieve their pain and other symptoms.

Why are medications used at the end of life?

Medications are commonly needed to manage symptoms, relieve distress and improve quality of life when someone is dying.

For example, medications can be used to prevent or manage nausea and vomiting, difficulty breathing, constipation, anxiety and pain.

When a person is prescribed palliative or end of life medication, it is not uncommon to have feelings of uncertainty or fear about the future and whether they are nearing death.

It is important to remember that appropriately prescribed and administered medication is a fundamental part of providing quality end of life care, and medication is not given with the intent to prolong life or to hasten death, but to ease symptoms.

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What are some common medications used at the end of life?

Medications for pain and breathlessness:

- *Paracetamol* (pronounced para-see-ta-moll)
- *Ibuprofen* (pronounced eye-byoo-pro-fen)
- *Codeine* (pronounced ko-deen)
- *Morphine* (pronounced more-feen)
- *Oxycodone* (pronounced ok-see-co-doan)
- *Hydromorphone* (pronounced hi-dro-more-phone)
- *Fentanyl* (pronounced fen-ten-all)
- *Buprenorphine* (pronounced boo-prenn-aw-feen)

The right pain relief for a person who is dying will depend on the type of pain they have and how intense it is.

Sometimes a combination of medications are used including:

- *paracetamol* and non-steroidal anti-inflammatory drugs (NSAIDs) for **mild pain**
- *codeine* for **moderate pain**
- *morphine*, *oxycodone*, *hydromorphone* and *fentanyl* for **strong pain**.

Some of these are short-acting medicines and some of these are longer acting medicines. Sometimes these medications are given as patches, injections or orally.

As someone nears the last few days or hours of life, they may experience pain or breathlessness, which can be distressing. Giving them small, regular amounts of morphine can help to keep them comfortable by easing their pain and helping them to breathe more easily.

If you think that the person is in pain or finding it hard to catch their breath, it is important to let care staff know.

Medication for restlessness or confusion

- *Haloperidol* or *Midazolam* (pronounced hal-o-PEAR-eeh-doll and mid-AZ-o-lamb)

People can become confused or restless in their last days of life. The medical word for this is 'agitation'. They may hallucinate or talk to people who are not there. They may be angry with family, carers and friends with no clear cause, and it may be hard to reason with them.

In some situations these medications, along with non-medication approaches, are used for settling agitation. Each of these medications can be given to people either as an injection or with other medications through a drip or syringe driver.

Medication that is given to manage confusion and restlessness has a relaxing and calming effect. It is common for people at this stage of life to only open their eyes or nod occasionally, and not wake easily. Sometimes they may stay asleep even when you talk or touch them. This is due to a combination of factors which may include their underlying medical condition (which is causing the agitation) and the medication.

It is important to let care staff know if you are worried that the person is restless or confused as they near the end of their life. It is better to manage their distress as soon as possible.

Medications to control nausea and vomiting

- *Haloperidol* and *Metoclopramide* (pronounced hal-o-PEAR-eeh-doll and met-o-CLO-pra-mide)

Not everyone will need medication to stop them feeling sick. If a person has felt sick or vomited, medication for nausea may be helpful.

Is addiction to morphine a risk?

Morphine is sometimes associated with drug addiction. But taking morphine for pain or to help breathing at the end of life will not cause addiction. Commonly, people worry when their dose of morphine increases. But the increase is usually because their needs have changed and more medicine is needed to manage the pain.

Medications for noisy or rattly breathing

- *Glycopyrrolate* or *Buscopan* (pronounced gly-co-PIE-ro-late or BUS-co-pan)

In the last hours of life, the person may begin to make a noisy, 'rattling' sound when they breathe. The noisy rattle comes from a build-up of spit (saliva) and mucus that they are no longer able to swallow or spit out. The noise of the rattle is often more distressing for family than the person who has the rattle.

Medication may be given to dry the mouth and reduce saliva so that fluid does not build up in the mouth. The medications can be given as a regular injection or included with other medication and given by a drip or syringe driver.

It is important to let care staff know if you begin to hear a 'rattle' sound when the person is breathing. Several things may help, including re-positioning the person and keeping their mouth moist. In some situations, medication may be helpful to reduce the build-up of fluids that make this sound.

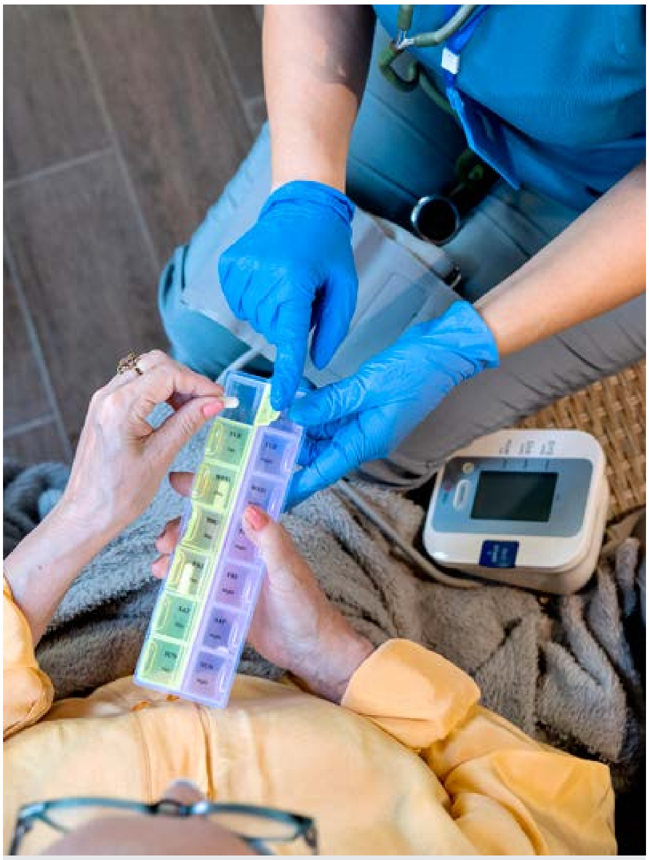
Who decides what medications are used?

Health professionals and care staff at the aged care service will involve the person (if they can make their own decisions) and their family or friends (if they person agrees for them to be involved, or no longer has capacity) in decision-making about medications at the end of life.

They may do this by holding case conferences to assist with communication, plan care, and make decisions relating to end of life in accordance with the person's wishes.

Where the person agrees to the involvement of family or friends, it is OK for them to ask questions, raise concerns with health professionals and care staff, and explore options.

Health professionals and care staff at the service may also connect with other health professionals who will form part of a multi-disciplinary care team. This team will work to provide integrated palliative care.



Questions about medications you may wish to ask when someone is dying

1. Is there anything else that may help ease my Mum's pain?
2. Dad is finding it difficult to breathe today – could medication help him?
3. How do you know Dad is not in pain?
4. Mary is finding that the injections are hurting. Is there another way she can receive the medication?

Conversations about the end of life

Having conversations about death and dying is an important way to prepare for death. While these conversations can be difficult, they enable shared understanding and involvement in end of life care.

Key actions the residential aged care facility will take to manage a resident's medication needs at end of life

- Regularly assess and respond to the person's changing medication needs, goals and preferences
- Rationalise (deprescribe) medications where they are no longer needed or are negatively impacting quality of life
- Withdraw futile or non-beneficial treatments
- Prescribe and administer medications to alleviate symptoms and suffering – particularly pain relief
- Enable the person to make informed choices and 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 decisions
- Communicate with and involve family or friends in discussions and care planning, when 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

- Older Persons Advocacy Network **Medication it's your choice**
- The Conversation **End of life conversations can be hard**
- 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.

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Transfers Between Care Settings – Client and Family

This pamphlet answers commonly asked questions about transfers between care settings at the end of life. Related pamphlets cover the topics of *Medication Management* and *Nutrition and Hydration* at the end of life.

Transfers of care

As people's needs change towards the end of life, they may need to be transferred between different health services or care settings. For example, a person might need to be moved to hospital for acute care or they may wish to go to a hospice for specialist end of life care.

As people nearing the end of life are more likely to have complex medical and care needs, it is important that transfers are carefully planned and managed.

Who decides to transfer a person?

It is preferable to minimise unplanned transfers for people nearing end of life. This can help to reduce any discomfort or risks to their safety or wellbeing and minimise distress and anxiety. A person's comfort and dignity takes priority at this time.

When considering a transfer, those responsible for coordinating the person's care will discuss options with the person (and if they wish, their family or support network), to see if they consent to being transferred, and how a transfer might be avoided. The person can refuse to be transferred.

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If the person does not have decision-making capacity:

- The person's directions about treatment and transfer in their valid Advance Care Directive must be respected by health professionals and care staff. A Directive that refuses transfer and treatment must be followed, even if it means the person's life may be at risk. Preferences, values and choices expressed in other advance care planning documents will also be taken into account to guide decisions about treatment and transfer.
- If the person does not have an Advance Care Directive, health professionals and care staff will consult a substitute decision-maker (this is sometimes a close family member or trusted friend) to make decisions about transfer, care and treatment. Their advance care planning documents (if they exist) should be taken into account to guide decisions about treatment and transfer.

There may be urgent circumstances (e.g., an emergency) where it may not be possible to gain the consent of the person (or their substitute decision-maker) to a transfer. In such circumstances, it is lawful to transfer a person without their consent or that of their substitute decision-maker.

Can a residential aged care facility support people to die comfortably?

Some people fear that dying in residential aged care will be unpleasant or impersonal. But dying in an aged care facility can be comforting, particularly if it has been a person's home for some time and they are familiar with the staff, and their friends and family can be present.

Residential aged care facilities are well equipped to provide 24-hour palliative care in a less clinical setting than in hospital. Nurses and others working in residential aged care have the skills and experience to provide quality end of life care that maximises a person's comfort and dignity. The aged care facility may also be able to support a person's family or friends to stay overnight during this time.

What does a well-prepared transfer look like?

If a person chooses to transfer (or needs to transfer to another care setting), it is important for this to be planned and coordinated to ensure there are no interruptions to care.

The person (and if they wish, their family, friends or supporters), will be involved in the planning. If the person does not have capacity to be involved, their substitute decision-maker will be included in planning. A transfer date will usually be planned in advance. However, there may be situations where transfer must be delayed, for example if the receiving service does not have arrangements in place or the person's condition changes.

The service transferring the person is responsible for handover information to ensure coordinated care is provided. This will include information about their condition, treatments, medications and their Advance Care Directive and/or other advance care planning documents (where these exist).

Arrangements will also be made to transfer the person's medications and personal items.

Transferring to a residential aged care facility

When a person is transferred to a residential aged care facility from hospital or another health service, the aged care provider may need to undertake a reassessment of their condition, needs and preferences. This may involve the person, their family or supporter (if they want them involved) or their substitute decision-maker (if they do not have capacity) and other health professionals, such as their regular GP or specialists.

The provider should ask the person about their specific preferences for their end of life care, including any cultural or religious needs. If the person cannot communicate about this (because they do not have capacity) the provider should work with their substitute decision-maker to understand their end of life care preferences, to meet their needs, respect their wishes and make them comfortable.

Transferring to home to die

A person may decide that they want to die at their home or a family/friend's home. In these circumstances, the aged care service can make arrangements to transfer the person so that their family, friends or supporters can care for them during the final days and hours of their life.

There are some support services available to help care for people at home as their death approaches. The aged care provider can help make the necessary connections and arrangements as part of the transfer process and provide information to support family or friends.

Conversations about the end of life

Having conversations about death and dying with family, friends, supporters, health professionals and care workers can be an important way to prepare for a person's death.

While these conversations can be difficult, they help to understand a person's preferences and how they want people to be involved in their end of life care.

Helpful questions about transfers

It may be difficult to find the right words or questions to ask health professionals and care staff when a person is dying.

If you feel like you don't understand what is happening or information is unclear, don't be afraid to ask questions. You have a right to understand why a transfer is happening.

Helpful questions about transfers when a person is dying

1. What will be the difference in care for my Dad if he is transferred to hospital?
2. How will the hospital provide better care for me?
3. If my Mum is transferred, will I be able to stay with her overnight?
4. If I am transferred to home, is there someone my wife can call to help her when she needs it?
5. If Dad is transferred to hospital, will he have to stay there until he dies?
6. How will the hospital know what Mum likes and doesn't like?
7. What could go wrong if we choose to transfer my sister to a hospice?

Key actions the residential aged care facility will take to manage transfers of a resident between care settings towards the end of life

- Discuss with the person where their preferred location to die is, and ensure this is recorded.
- Enable the person to make informed choices about transfers and respect their right to refuse to be transferred and to refuse treatment.
- Work with the person to avoid any unplanned or unnecessary transfers.
- Follow relevant directions in the person's Advance Care Directive including refusals for transfer or treatment.
- Ensure any transfers are underpinned by effective planning, risk management, coordination, and communication with everyone involved.
- Facilitate continuity of care between settings by sharing current and comprehensive information about the person's needs and preferences with those involved in their transfer and subsequent care.
- Ensure adequate supports are in place if the person is transferring to a private residence (e.g., a family home).
- 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.

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Helpful resources

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The Conversation End of life conversations can be hard

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