



End of Life Care

Introduction

Care of a resident at the end of life is a distinct and important part of residential and community care. The sections of this resource are designed to support you in the delivery of optimal end of life care.

Within the current Aged Care Standards, Standard 29 requires that

“The comfort and dignity of terminally ill residents is maintained”.

In order to achieve and demonstrate this standard at the end of life, particular knowledge, understanding and skill are needed. Further, the achievement of this Standard at the end of life will require the contribution of many providers, the coordination of those contributions, and sensitive communication with the dying person and their family and/or carers.

Aged care staff have been delivering end of life care for decades. However, there are continuing changes in the characteristics of persons entering care that increase the likelihood that end of life care will be part of a resident’s experience at their facility. There is a trend of decreasing length of stay in high care facilities, with residents more unwell on arrival. There is also a trend in low care and (sometimes) community care for an individual’s changing needs to be met in their present location wherever possible. This is an expression of the policy direction known as Ageing in Place, and the logical extension of that policy could be termed “Dying in Place”.

Completing this resource will place you at the forefront of end of life care delivery. Before moving on, consider the following questions to help focus on the units ahead.



Take a moment to think about people who have died in the last 6 – 12 months in your facility or service. Select one or two examples if possible. If you have had no contact with any deaths in that time you might like to discuss the following with a more senior staff member.



Writing activity

Write down quick responses to the following questions:

Was the death expected? _____

Was it a “good” death in your view? _____

What aspects of care do you believe were well done by your facility?

Were there any events or aspects of care that you would have liked to have been handled differently?

The remaining sections of this resource will cover many of the central aspects of end of life care. Topics relating to *Communicating with Family* and *Grief and Bereavement Care* will be addressed in other resources available on the PCA website www.pallcare.org.au.

Topics to be covered are:

Module 1. Recognising the end of life phase

Module 2. Planning for the end of life

Module 3. Managing end of life care – a pathway approach

Module 4. Providing end of life care - physical symptom relief

Module 5. Providing comfort care at the end of life

Module 6. Non physical elements of end of life care

Module 7. Post death care

Module 8. Ethical dilemmas in end of life care

Module 9. Quality issues in end of life care

You are encouraged to have access to a copy of *Guidelines for a Palliative Approach in Residential Aged Care* while completing this resource. This will be referred to as the *Guidelines*.

Note that two editions of the *Guidelines* exist. These were published in May 2004 and May 2006 (Enhanced version). Users of this resource should use the guideline references that apply to the edition they have access to.



Writing activity

To conclude this introduction, take a moment to identify 2 or 3 things that you most hope to learn by the time you finish this resource on end of life care.

1. _____
2. _____
3. _____

Module 1: Recognising the end of life phase

Learning outcomes

By the end of this section the learner should be able to:

- Demonstrate an understanding of illness trajectories
- Recognise common signs and symptoms of the end of life phase

Illness trajectories

Different diseases and conditions have differing effects on the approach to the end of life. The *Guidelines* present an overview of the differences between three common pre death conditions.



Read the *Guidelines* section 13.2 of on pages 138 – 139 (original version May 2004) or section 14.2 on pages 162 – 163 (enhanced version May 2006)

The concept of trajectories captures much of the difficulty in knowing when the end of life phase of an illness begins. Traditionally persons with advanced cancer have had a degree of predictability around the progression of their disease. While there are always exceptions the end of life phase for persons with advanced cancer is marked by a steady, recognisable deterioration in condition. In part this was why traditionally specialist palliative care services were closely linked to cancer.

For persons with organ failure, such as chronic heart disease or lung disease, the progression of the disease is characterised by periods of severe deterioration (exacerbations) followed by improvement (although rarely to the same level). Each episode of deterioration has the potential to be the beginning of the end of life phase.

Advanced dementia has a more difficult illness trajectory to track. As illustrated in the above reading, there is a progressive deterioration in condition, but this can be over an extended time period. Persons with advanced dementia can be very unwell and very withdrawn for months.



What has been your experience of person who died with advanced dementia? Would you have seen them as being in the end of life phase a week before they died? a month before? three months before?

Many persons in aged care have more than one illness or condition, and this can make it even more difficult to identify the point of entry to the end of life phase.

Indicators for the transition to end of life phase

For progressive illnesses, the closer a person is to death the clearer it is that they are dying. There are, however, a number of clinical indicators that point to the transition to end of life phase, a period that can be described as weeks to months. For persons with dementia these include:

- Serum albumin < 25
- Dual incontinence
- Reduced oral intake
- Fewer than 6 intelligible words
- Difficulty swallowing / eating
- Weight loss

Impending death is often heralded by loss of consciousness and lack of responsiveness (days to weeks), with changes in breathing and circulation indicating a timeframe of hours to days. See Module 7 in this resource for additional detail on imminent death.

Summary box: Module 1

In many non-cancer conditions the end of life period can be difficult to map.

The end of life is clearer as it becomes nearer.

A number of clinical indicators have been identified that point to the end of life phase.

End of life care processes need to be sensitive to this uncertainty where it exists

Module 2: Planning for the end of life

Learning outcomes

By the end of this section the learner should be able to:

- Identify steps that can be taken to prepare for end of life care
- Demonstrate an understanding of the contributors to end of life care

End of life planning

Optimal end of life care requires planning well before the last days of life. Staff need to confirm the existence (or otherwise) of an advance care plan or directive as this will provide direction to care.



If you have not recently done so, review the *Guidelines on Advance Care Planning*, pages 33 – 39 (original version May 2004) or pages 55 – 59 (enhanced version May 2006)

When an advanced care plan or directive exists, the care team can be informed by it and incorporate it into the end of life plan.

When no plan or document exists, the family or carers need to be consulted as soon as practicable.



Read the *Guidelines* section 13.4.6 on pg 144 (original version May 2004) or section 14.4.6 on pages 167 – 168 (enhanced version May 2006)

Guideline 79 (original version May 2004) or Guideline 75 (enhanced edition May 2006) states the following:

“Well-planned family conferences, conducted in private and attended by the GP and other members of the aged care team, provide an opportunity for building trust and discussing end-of –life issues of concern.”



The end of a loved one’s life is usually a time of stress for families, and they can respond to care staff in a range of different ways. Think about a recent occasion when a family member responded in a negative way towards you or other care staff during an end of life period for a resident.



Writing activity:

Using this example, make a response to the following questions.

What was the main concern or problem this family member expressed?

How might a family conference at the time have helped this situation? (Or, if one had been held, why did it not seem to help?)

Remember that the end of life period is a time of uncertainty for family members, many of whom may not have closely experienced the death of a loved one before. They will need the guidance of the care staff as to what they can expect (in terms of the dying process) and what they can do (in terms of being with their loved one, and in terms of assisting in care).

Planning for the end of life period will require clarification of the role of the Medical Practitioner, especially in terms of availability after hours. Once clarified this information requires clear documentation for the benefit of care staff.

Preferred place of care may be informed by previous advanced planning, by the family or by the previous expressed wishes of the resident. A clear direction about what, if any, situations would warrant transfer to hospital needs to be documented at the beginning of the end of life care period. Guideline 2 (original version May 2004) or Guideline 3 (enhanced version May 2006) states that:

“Implementing a palliative approach in RACFs can reduce the potential distress to residents and their families caused by a transfer to an acute care setting.”

This is especially so at the end of life. Family members will need sensitive reassurance about the range of appropriate care that the facility can provide in this context.

The role that may be played by other services needs consideration and planning. Other services may include:

- the nearest specialist palliative care service – what is the indication for their involvement?
- relevant spiritual care resources – identify and contact.

All of these things are part of planning in end of life care. It has been said that “failing to plan is planning to fail”. Quality and optimal end of life care is achieved only where relevant and essential matters are identified, discussed, determined and documented in advance.



Other planning elements are summarised in the *Guidelines* in section 13.5 on page 145 (original version May 2004) or section 14.5 on page 169 (enhanced version May 2006) Review these now.

Summary box: Module 2

End of life care is enhanced by planning ahead.

Family conferences can aid end of life planning.

Preferred location, scope of interventions and role of other providers are aspects of end of life planning.

Module 3: Managing end of life care – pathways and care plans

Learning outcomes

By the end of this section the learner should be able to:

- Describe the scope of end of life care
- Consider the value of written plans of care
- Recognise the importance of well documented care

Capturing the scope of end of life care

While many care staff would claim to deliver quality end of life care, it is necessary to demonstrate that such care is planned and delivered. This need for planned and documented end of life care is common around the world, and has resulted in the development of end of life care pathways. In the 1990s the Liverpool Care Pathway for the dying was developed to assist care providers across all care settings (including aged care) to have confidence that they were delivering best possible end of life care, and that the care given was well documented. In this decade the Liverpool pathway has been adapted for Australian care settings in several states. One example of this is a NSW Central Coast Health version that is presented as Appendix 1.



End of life pathways are built on the observation that all persons, regardless of disease process, experience similar needs and similar symptoms during the last days of life. Further, end of life pathways are built on an expression of care linked to best known practice and best available evidence.



Take time to locate and identify the type of documentation your facility or service uses to guide / direct / plan end of life care.

Pathways are not the only way of planning and documenting end of life care. However, they are useful points of reference for local care plans.

Examining the items included in an end of life pathway is one means of describing the key elements of care for residents who are dying.



Look at the End of Life Care Pathway in Appendix 1, and also your local documentation. Note the following elements.

1. An assessment that death is approaching. This needs to be a medical determination in order to initiate a review of medications. It also helps to signal to family, carers and other staff that the end of life phase is being acknowledged.
2. A review of current medications. The goal at the end of life is to continue / introduce only those medications that directly contribute to comfort. Indicated medications should be readily available for administration.
3. A review of medication route. If the oral route of administration is not reliable or absent, the most suitable alternative needs to be identified. In Australia, the subcutaneous route is common, although some medications can be absorbed through the oral mucosa in the mouth (the buccal route).
4. Confirmation of contact information. Clearly document the person responsible / key family member and their contact details and preferences. Not everyone will want to be contacted in the middle of the night.
5. An encouragement to address immediate concerns of the family that may arise at this transition. Check that required information about post death arrangements is documented.
6. Recognition and clear documentation of any religious / spiritual or cultural requirements.
7. A care environment review. Is the resident's current location within the facility suitable? What options exist if a change is indicated? Are pressure relieving devices in use / available?
8. A shift in ongoing observations and assessments to focus on end of life comfort issues. Observations that aid the comfort process are undertaken in a way that complements the provision of end of life care.
9. An encouragement towards providing bereavement support or providing information about this.
10. An evaluation process to review and inform end of life care.



When you have previously been involved in providing end of life care were these ten points part of the plan of care?



Writing activity

Are there items you believe are part of end of life care and are not included in the above ten points. If so, make a note of them.

The use of an end of life pathway or care plan provides a number of key benefits for those with responsibilities in providing end of life care.

1. Known best practice can be used to guide the plan of care.
2. Evidence of delivered care is readily documented.
3. A process of continuous improvement can be supported.
4. Quality care is delivered with greater consistency across multiple sites.

Written plans for care of all types have the advantage of ensuring a common understanding and delivery of the important aspects of end of life care. Whatever approach is used there needs to be flexibility to address individual differences or circumstances. Ongoing review and problem solving are also critical elements to be built into approaches to end of life care.

In addition to being a means of demonstrating the delivery of quality end of life care, written formats support care staff by helping them to be confident that the care needs identified are the ones that are most important for a resident who is dying. End of life care pathways offer a clearly articulated common goal for care providers.

Summary box: Module 3

Pathways or pre-written plans of care assist in the identification, delivery and documentation of optimal end of life care.

These guides support care providers by focusing on the known essential aspects of end of life care.

Clear documentation of end of life care aids communication with all care providers.

Module 4: Providing end of life care – physical symptom relief

Learning outcomes

By the end of this section the learner should be able to:

- Identify the key physical symptoms in end of life care
- Recognise the importance of ongoing assessment
- Understand principles of pharmacological management (RNs)

Key physical symptoms in end of life care

In the last days of life physical symptom management has two aspects.

Firstly, existing symptoms must be managed. If pain or difficulty with breathing has been a presenting problem prior to the end of life period, then the management strategies in place are continued. These strategies are reviewed if symptom relief is less than optimal.

The second approach is to anticipate symptoms that may not be presenting currently, but that can be anticipated. Experience in the United Kingdom has indicated that four key symptoms can be present at some time in the last days of life, either singularly or in combination. These are:

- Pain
- Nausea / vomiting
- Respiratory secretions / distress
- Agitation / restlessness

When these symptoms are anticipated, plans can be put in place to respond in a timely way should they occur during the last days of life.



Writing activity

Before continuing, write down the symptoms / problems you remember a resident having during the last days of their life. Alternatively you could ask other care staff to identify physical symptoms they have encountered during a resident's last days.

Pain in the end of life period

Pain as a topic is addressed in detail in the *Pain Assessment and Management* resource available on the PCA website www.pallcare.org.au. The purpose of this section of this resource is to focus on the process of managing pain in the last days of life.

Pain is a symptom that can occur in the last days of life. The causes of pain in the dying vary depending on diseases (pathologies). Pain may be a known symptom prior to the last days of life, or may occur for the first time during this time.

In terms of medication for pain, two different approaches are used:

Pain not a current symptom

If pain is not an existing / known problem at the start of the end of life phase, overseas best practice suggests that a PRN dose of analgesia be ordered in anticipation of the reasonable possibility that pain will present during the last days of life. However, if PRN doses are being given more than 3 or 4 times in a 24 hour period, a more regular analgesia schedule may be indicated.

Pain is a current symptom

When pain is a pre-existing symptom, measures should be in place to ensure continued effective management during the end of life. This means that the existing strategy is reviewed (is it effective?) and continued (or changed). If medication is being administered, the route of administration is changed if needed (e.g. to subcutaneous injection).

If the existing pain is of an ongoing nature (chronic or persistent), the recommended approach is to administer regular doses of analgesia (by the clock). In addition, a PRN order for additional doses (breakthrough or rescue) should be given where indicated.

Goal

The end of life goal is that the individual be pain free.

Assessment

All aged care clinicians acknowledge the need for regular assessment of symptoms. The challenge in end of life care is that the resident is often unable to contribute to this assessment. In pain management it is considered best practice to use a non verbal (behavioural) pain assessment tool. (See Guideline 20 (original version May 2004) or guideline 19 (enhanced version May 2006)). Examples include the Pain Assessment In Advanced Dementia Scale (PAINAD) and the Abbey Pain Scale.

The difficulty in assessing pain at the end of life in residents who are unconscious or severely cognitively impaired is not to be underestimated.

 It is most important that the care team discuss pain assessment and reach an agreement on which behavioural cues are pain related and agree to respond in a consistent manner.

When pain is assessed and ordered analgesia is administered, its effectiveness needs to be determined. This may be done by observing and re-assessing the resident at a period of time related to the route of administration and the medication itself.

 All episodes of pain and its management need careful and consistent documentation. This will aid other members of the care team, especially if a review of medications is indicated.

Where pain management strategies are not succeeding consider asking for an opinion (consultation) from the local specialist palliative care service.

Nausea / vomiting in the end of life period

Although initially included in the set of key end of life symptoms, nausea / vomiting is known to be a less commonly experienced problem than pain.

The principle of management follows the same pattern as for pain.

Nausea / vomiting not a current symptom

If nausea / vomiting is not an existing / known problem at the start of the end of life phase, overseas best practice suggests that a PRN dose of antiemetic be ordered in anticipation of the possibility that an episode will present during the last days of life. However, if PRN doses are being given more than 3 or 4 times in a 24 hour period, a more regular dosing schedule may be indicated.

Nausea / vomiting is a current symptom

If nausea / vomiting has been an identified problem at the start of the end of life period, the existing management strategy is reviewed (is it effective?) and continued (or changed). When medication is being administered, the route of administration is changed if needed (e.g. to subcutaneous injection).

Goal

The end of life goal is that the individual has no episode of nausea / vomiting.

Assessment

The particular challenge for prescribers in managing nausea or vomiting is to match the medication to the cause of the problem. There are a number of different processes in the body that can result in nausea / vomiting. These include stimulation of the:

- Chemoreceptor Trigger Zone (CTZ)
- Gastrointestinal tract
- Vestibular apparatus
- Vomiting Centre

In end of life care the drug of choice may be related to the cause of the nausea / vomiting stimulus (if known) or may be selected because it has combined anti emetic and sedative effects (e.g. Haloperidol). The resource entitled *Symptom Control* on the PCA website addresses the symptom of nausea/vomiting in more detail.

If this symptom occurs then clear documentation of assessment, intervention and response will assist in ongoing clinical decision making.

The introduction of nasogastric tubes in end of life care is usually avoided due to the added discomfort of the tube, and the ability to manage symptoms with medication.

Respiratory secretions and respiratory distress in the end of life period

Respiratory secretions

Of all the symptoms encountered at the end of life respiratory secretions can be the most troubling for family and care staff. Noisy respirations, sometimes called “death rattle” will occur in a large number of cases. For the unconscious person themselves these secretions are not believed to be a source of distress.

There are a number of considerations in managing respiratory secretions.

- As the likelihood of occurrence is high, a PRN order of an anticholinergic drug is a recommended practice at the beginning of the end of life phase. The medication administered is designed to suppress or minimise the production of secretions. It will have no effect on existing secretions. For this reason the medication should be administered at the first sign of accumulating respiratory secretions.

Hyoscine Hydrobromide is a suitable agent for unconscious or semi-conscious residents, but may be effective in only about 50% of cases.

Glycopyrrolate is an alternative for more conscious residents. Also Hyoscine Butylbromide.

- Positioning on the side can be effective in some cases.
- Suctioning in end of life care is not usually indicated.
- Family and others will need reassuring that noisy respirations are not causing distress to

their loved one.



See the *Guidelines* section 13.4.3 on page 143 (original version May 2004) or section 14.4.3 on pages 166 – 167 (enhanced version May 2006) to review.

Respiratory distress (dyspnoea)

For some conditions dyspnoea (or breathlessness) is a symptom existing before the end of life period is reached. It is a common occurrence in the last days of life.

Low dose morphine (subcutaneous injection) has been shown to reduce dyspnoea without significant respiratory depression.

Anxiolytics (benzodiazepines) may reduce dyspnoea, especially when anxiety/ fear is a contributing factor.

Oxygen may relieve the dyspnoea associated with hypoxia.

Respiratory distress is managed in response to the underlying cause. However, in the conscious and cognitively intact resident psychological factors related to the experience of dyspnoea will be a consideration. For the unconscious resident the primary management of dyspnoea in the end of life period is with morphine.



See the *Guidelines* Section 13.4.4 page 143 (original version May 2004) or section 14.4.4 on page 167 (enhanced version May 2006) to review.

Agitation / restlessness in the end of life period

Agitation or restlessness may present in the last days of life. There can be multiple causes, but these will be able to be identified in only 50% of cases.

A general principle of care is to reverse the reversible where this will provide increased comfort. This means that if the cause of agitation or restlessness can be identified, and if the cause can be removed without undue distress to the resident, a strategy should be implemented.

Possible causes of agitation / restlessness include:

- Physical discomforts (e.g. pain, full bladder / bowel, pressure areas)
- Anxiety or existential distress
- Drug toxicity. For example, if a resident in the last days of life is receiving opioid medication and develops agitation / restlessness, observation for myoclonus (involuntary muscle jerking or twitching) and other possible signs of morphine toxicity should be included in their assessment.

- Hypoxia
- Metabolic imbalances
- Environmental factors. As well as medication, environmental factors may help reduce restlessness. Can noise be reduced? Does the resident seem more settled with the lights on or off at night? How does the resident respond to gentle touch?

If a reversible cause is not identified, administration of benzodiazepines (eg Midazolam, Clonazepam) is the identified practice. It is recommended that a PRN order be included at the start of the end of life period.

Other physical events in the end of life period

Haemorrhage

For a very small number of conditions there may be a risk of sudden and catastrophic haemorrhage as an end of life event. If a dying resident in your care has been assessed to be at risk of a sudden life ending bleed, then the following steps form part of the management of that event.

- An order for a sedative agent is put in place (e.g. Midazolam 10mg). Administration is intramuscular rather than subcutaneous.
- Dark green or blue towels are readily available (for external bleeding).
- If an anticipated life ending haemorrhage occurs, then a care team member should stay with the resident.

Summary box - Module 4

Existing symptoms require continuing management during the last days of life.

In addition, several common potential symptoms occurring in the last days of life have been identified.

Recognition of these potential symptoms allows planning for their occurrence, enhancing comfort.

Module 5: Providing comfort care at the end of life

Learning outcomes

By the end of this section the learner should be able to:

- Identify the key aspects of maintaining comfort in end of life care
- Recognise the importance of ongoing assessment
- Describe strategies that support the provision of comfort care

Ensuring that a resident is as comfortable as possible is part of aged care at all times. During the last days of life, this goal has an even greater priority. However we may individually describe “a good death”, being uncomfortable is not part of the picture.

This section will look at several aspects of end of life comfort care.



Take a moment to reflect on how you and your co-workers help to provide comfort care for residents in the last days of life. What things, if any, seem the most important (or are given the highest priority.)?

Eye care

During the end of the life period, and possibly well before then, the resident may be dependent upon care staff for eye care. The care goal is that eyes are clean and moist. The challenge is to achieve this goal with the frequency of intervention that is specific for each resident.



Gentle eye toiles are used following local procedure. Eye lubrication is indicated if eye is dry e.g. Liquid Tears (or similar products), normal saline.

Mouth care

Mouth care takes on a particular importance in end of life care. Moist, clean oral mucous membranes are believed to prevent a dying individual’s perception of thirst. When regular mouth care is provided during the end of life period, the resident experiences both the comfort of a clean, moist mouth and the comfort of not experiencing thirst despite little or no fluid intake.

The care goal is that the mouth and lips are clean and moist. The mouth and lips are reviewed regularly.



Moist oral mucous membranes will tend to prevent thirst. Local protocols for cleaning mouth and dentures are used. Avoid alcohol based agents as these can exacerbate “dryness”

Positioning

Positioning is a comfort care consideration that can be a challenge in the end of life period. The care goal is that a comfortable position is maintained. It is the frequency of repositioning that requires an individualised approach.

The potential conflict in this care (and it is related to skin care) occurs when repositioning directly causes distress for the resident. The care team can respond to this by realistically evaluating how often this individual needs to be moved. This can be difficult as there may be no certainty as to how many more days the resident will be alive. Regardless, it is an important aspect of person centred end of life care to regularly review the plan for repositioning, and to reduce this where possible in the last days of life.

Use pressure relieving devices where possible.

Use the resident’s “preferred” position as often as reasonable. This may have become evident during the pre end of life period, and is used if the resident is noticeably more settled when in that position.

When necessary repositioning causes distress due to pain, this can be managed as “incident pain”. When incident pain is anticipated, appropriate PRN analgesia can be administered at a suitable time before repositioning occurs.

A related challenge is to try to distinguish between incident pain and distress that may be psychological in origin (such as anxiety). It is desirable to administer the right medication for the presenting problem, and analgesia is not the best option for fear and anxiety based distress.



Realistically minimise repositioning if distressing to resident. Use pressure relieving devices if available. Anticipate and manage incident pain.

Skin care

A realistic and individualised approach to skin care is needed in the last days of life. The above discussion on positioning applies to prevention of pressure areas. Again, the comfort of the resident is the priority and potential skin breakdown is managed by a range of strategies with repositioning minimised where possible. Existing wounds are managed conservatively with protective, low frequency dressings. Each individual needs to be observed for their response to touch when gently applying moisturising lotions. Some will be comforted while others may become agitated.

The care goal is that skin be clean and not allowed to become dry.



Avoid products that dry or harm skin. The need for pressure area care should be balanced against the need for comfort. Wounds should be managed in the least invasive way (no time to heal). If incontinent ensure skin protection products are used.



For comments on positioning and skin integrity see the *Guidelines* Section 13.4.1 page 142 (original version May 2004) or section 14.4.1 on pages 165 – 166 (enhanced version May 2006) to review.

Elimination

During the end of life phase oral intake of both food and fluid reduces. Renal function declines and urine output decreases. The end of life care goal is that the resident be dry and comfortable.



Urinary aids such as pads are used if resident is incontinent. Urinary retention should be excluded if the resident becomes restless. Catheterisation is used to relieve urinary retention, however it is not left indwelling unless seen as essential for comfort.

Bowel products also lessen in quantity as the end of life approaches. The end of life care goal is that the individual is not agitated or distressed by constipation or diarrhoea.



In the last days of life, if oral medications are not possible, bowel management agents are not routinely used. A full rectum should be excluded if the individual becomes restless (use suppositories). Skin protection is vital if resident is faecally incontinent.



You can find a useful summary of elimination issues in the *Guidelines* Section 13.4.5 (pg 144) (original version May 2004) or section 14.4.3 on pages 166 – 167 (enhanced version May 2006) to review.

Summary box: Module 5

Comfort care is the primary focus during the last days of life.

Mouth care plays an important role in managing thirst.

All care involving movement or repositioning needs individualised review to minimise distress.

Module 6: Non-physical care at the end of life

Learning outcomes

By the end of this section the learner should be able to:

- Recognise the importance of early identification of spiritual / religious / cultural requirements
- Identify the importance of information for family during end of life care

Spiritual/religious/cultural concerns

Within our diverse society there are a wide range of beliefs and practices around the end of life. As aged care workers there is an obligation to try to meet each resident's expectations about the rituals and practices that are of importance to them and their family.



Chapter 11 of the *Guidelines* (May 2004) considers spiritual support mostly from a pre end of life perspective. Note Table 13 on page 131, and Guideline 73 on page 133. (original version May 2004) or Table 20 on page 153, and Guideline 70 on page 155. (enhanced version May 2006) to review.

Understandings, expectations and practices relating to dying and death vary for each individual. Quality end of life care needs to address what, if any, spiritual, religious or cultural factors are important for each individual and their immediate family during this time.



Take a moment to think about particular rituals or practices relating to death that were important for someone you know who has died.

It is important to note that relevant rituals, observations, practices or process may apply

- Pre death
- At the time of death
- Post death

Examples include:

- The performing of rituals or prayers before and / or after death
- The particular position or orientation of the person at the time of death

- Preferences for how the person is to be washed, dressed or handled after death.

It is essential that expectations or needs in this area are noted early and clearly documented. Identifying needs and facilitating their observance will support the individual and their family.



Always take an individual approach. Avoid assumptions and stereotyping. If indicated, facilitate the practice of identified rituals and provision of support. Utilise family contacts / resources. Negotiate the introduction of other pastoral resources if indicated. Exercise cultural awareness and make use of available resources.

Psychological care

As the last days of life are often characterised by unconsciousness for the resident, the primary focus of psychological support is for the family or carers who are present during the end of life period. Other resources on the PCA website www.pallcare.org.au will look at communicating with the family and grief and bereavement support. This section of the resource will seek to emphasise the importance of information in end of life care for family members.

The quality and timing of information impacts on the end of life experience of the surviving family / carers. For most people the death of a family member is infrequent, and they may have little experience of the process and its impact. There is a need to clarify with the family how much information they want and who should be the primary contact person to receive information. Who has a ‘right’ to the information?

Frequent explanation and reassurance about what is happening in the dying process may lessen carer concern. Helping them to be aware of “what usually happens next” minimises the uncertainty about changes that are occurring during the last days of life.



See Guideline 78 page 147 (original version May 2004) or Guideline 70 on page 171. (enhanced version May 2006) to review.

Communicate using language that the family can understand. If indicated it is desirable to use a health interpreter and not a family member.



See *Guidelines* sections 10.1 & 10.2, pages 125- 126 (original version May 2004) or sections 11.1 - 11.4 on pages 148 - 150 (enhanced version May 2006).

When communicating with family members try to stay focused on the known facts, and avoid the temptation to “fill in gaps” with what you think is happening. It is acceptable to say “I don’t know the answer to that question”, but important to direct to someone who does.

Avoid jargon. It is easy to forget that some words, expressions and understandings used in our workplace are not commonly understood by others. Use clear language.

Families benefit from being kept up to date; therefore it is helpful to inform them of changes or medical reviews where possible. This process builds trust between the family and the facility / staff.

Work through the nominated primary carer and direct others to that person. If problematic a family meeting may prove useful and both the discussion and any decisions should be clearly documented.



For additional information see Guideline 79 on page 147 and section 13.4.6 on page 144 (original version May 2004) or Guideline 75 on page 171 and section 14.4.6 on page 167 (enhanced version May 2006).

In addition, it can be useful to document discussions with family /carer in the progress notes, in order that other workers will know what has been covered previously.



Be aware that quality communication in the end of life context requires sensitivity. Communication for family members is enhanced if they perceive that you share their concern for the resident. Avoid offhanded or rushed communications. Stay focused on their immediate needs. Prepare then for anticipated changes as the last days progress.

Summary box: Module 6

Early assessment and recording of spiritual / religious / cultural requirements around the end of life will help facilitate their provision.

Spiritual / religious / cultural requirements may occur prior to death, at the time of death, and after death.

Families require sensitive and timely information about events as changes are anticipated and as they occur.

Module 7: Post death care

Learning outcomes

By the end of this section the learner should be able to:

- Describe the indicators of imminent death
- Identify the signs of death
- Recognise the processes to be observed post death

Imminent death

As mentioned in the earlier section in this resource entitled recognising the end of life phase, different illnesses and conditions are associated with different levels of certainty and predictability about the pre-dying period. Despite that, the progression through the last hours of life looks more similar than different (although exceptions always occur) for various conditions.

Weakness, fatigue, lethargy are common. Unconsciousness is normal, although some will have periods of semi-consciousness. Respiratory secretions may be present, resulting in a moist, gurgling breath. Respiration rate decreases, although some conditions may result in a period of Cheyne-Stokes respirations, which is described as a set of rapid breaths with changing depth punctuated by periods of no breathing (apnoea). Renal function declines, and what urine is produced will be dark in colour. Peripheral shutdown occurs as the body prioritises its central organs. This results in cool or cold extremities. Heart rate may initially increase although the strength of the pulse will weaken. Some peripheral fluid pooling may occur due to low albumin levels.

It is generally accepted that the unconscious person can hear until death occurs. Although difficult to prove, this should be presumed by family and care providers.

Signs of death



Read the *Guidelines* section 13.6 on page 146 of (original version May 2004) or section 14.6 on page 169 (enhanced version May 2006).

The physical presentation of death is objective. In most care settings the cessation of breathing and heartbeat are taken as clear indicators of death.

When death is near it may be useful to encourage any family members staying with the resident to seek a staff member should they believe the resident has died. Note that different individuals report a range of “perceptions” at the time of death, from an intense silence to a sudden feeling of coldness. Care staff do not need to try to explain or accept such experiences, but rather be supportive and non-judgemental of family members should they report an unusual experience at the time of a death.

After death care

Spiritual or cultural requirements may guide the specifics of care following death. Also, law and procedures relating to death and after care will have some variance across the states and territories.



For a general overview of matters to be considered or followed after a death has occurred read the *Guidelines* section 13.7 on pages 146 - 147 (original version May 2004) or section 14.7 on page 170 (enhanced version May 2006).

Regardless of other requirements it is positive for family members to be given time and space to say goodbye to the deceased resident if that is their wish.

During the immediate post death period emotional distress is common and normal, and it can be easy to feel helpless in the midst of other's grief. You can be helpful by remaining available to answer any questions. Also, the simple act of offering a drink of tea or coffee (or water) can be a welcome one, as it is a familiar event in the midst of the unfamiliar experience of a death.

The importance of planning

Quality end of life care is dependent upon good planning. Post death care is also improved by giving attention in advance to those matters that can be discussed and documented before the event.

Arrangements for the certification of the death need to be known before the event. When a resident's condition is deteriorating before a weekend or public holiday period alternative arrangements, if needed, require clarification. Similarly, the name of a funeral director (or other) is best known before a death, as decision making post death can seem burdensome and difficult for a grieving family. The availability of any required spiritual or cultural resource needs to be confirmed as well.

Finally, the capacity of different facilities and services to provide bereavement care or support is varied. A minimum level of care would be to ensure that family members have information about local bereavement services / groups or other supports before they leave the facility.

Summary box: Module 7

Death may be unfamiliar to family members.

Provide attending family as much time as is possible following a death.

Provide information about available bereavement support / services.

Module 8: Ethical considerations in end of life care

Learning outcomes

By the end of this section the learner should be able to:

- Demonstrate and understanding of the role of nutrition and hydration in end of life care
- Recognise the role of correctly administered analgesia in end of life care
- Identify steps in resolving ethically complex care decisions

One of the characteristics of end of life care is that issues around individual values become more apparent than they seem to be at other times. The values of the individual resident, of their family, of their attending medical officer, and of the care staff are not always in complete agreement.

When we speak of ethics we are speaking about values, about principles and standards that guide our view of what is good or bad, right or wrong. In health care, and especially in end of life care, situations arise when we may find ourselves uncomfortable with treatment decisions or approaches. This discomfort may arise from a tension between our own values, and those of others involved in the particular care example.

The study of ethics can be complex, and is beyond the scope of this resource. This section will introduce a number of key ethical ideas, and look at the common issues that arise in end of life care.

Ethical reference points

There are a number of well known value positions that can have some connection with our personal view. Three of these are discussed here.

The concept of Respect for Autonomy refers to the fact that each person has the right to make decisions for themselves, to have control over their own life. In end of life care this position supports the use of advance care plans or directives that represent the resident's wishes about care types and limits.

The concept of Beneficence, (or doing good) refers to the fact that it is always important to act in the best interest of the resident. When treatment or care decisions are made, the guiding principle is "what is best for this person". End of life decisions about continuing to provide fluid or nutrition may be presented from a belief that the best thing to do for this resident is to provide (or not provide).

The concept of Nonmaleficence refers to not deliberately causing harm. In end of life care this concept can be difficult as the idea of what harm is may become complex. Staff who are reluctant to administer prescribed strong analgesia (eg morphine) may mistakenly believe that they will cause harm (meaning death) if they do so.



Think again on a recent death. Were there specific moments when you felt uncomfortable or ill at ease about aspects of the care that was (or was not) given to the resident?

 **Writing activity**

If there were such moments, write down the specific item/s or event/s that you remember.

 Now, try to identify what value of yours was at the centre of your discomfort or disagreement. What did you think was the better thing to do?

Common ethical issues

There are a number of common ethical issues that can occur during the end of life period:

Nutrition and hydration

Both food and drink are strongly associated with our perception of living. A resident's inability to self care in these areas is a common, though at times difficult, landmark point. When assisted feeding and/or drinking is no longer possible, choices need to be made based on the resident's condition and prognosis.

As the end of life period advances perception of hunger is reported to diminish by those who are conscious and cognitively unimpaired. Starvation at the end of life is not a reported sensation, due to the chemicals being released by the body at this time. Artificial feeding tubes in persons with advanced dementia have not been shown to extend life, and have their own risks including aspiration. Decisions around feeding tubes and the end of life are difficult ones, and are best approached by a consideration of real risks and benefits based on facts rather than perceptions.

Artificial fluid administration is rare in aged care. However, it is not uncommon to have family members insisting that artificial hydration (and nutrition) be given. When a decision to provide artificial hydration and/or nutrition is made some care staff may perceive that the benefit is for the family rather than the resident.

It is to be noted that artificial hydration at the end of life has risks in terms of contributing to fluid overload, oedema, and other discomforts. There is no clear evidence of benefit from artificial hydration at the end of life.

These are not easy decisions and differences of view are common. An individualised approach based on each resident's particular clinical situation is the starting point in resolving these care decisions.

Euthanasia

The term euthanasia has multiple dimensions to its meaning, although the usual context is around a person who is dying and has poor quality of life. Commonly it is used to mean "the intentional ending of a person's life as requested by that person" (voluntary euthanasia). This is illegal in Australia.

For persons who are unable to speak for themselves, a request may be made by family members to advance a resident's end of life. This may be called involuntary euthanasia. This is illegal in Australia.

Analgesia

Medications used during end of life care, especially opioids (e.g. morphine) are sometimes believed to have a life shortening effect. Some care staff may even be reluctant to administer prescribed medication for fear the resident may die. These beliefs are based on misunderstanding.

Proper administration of appropriate symptom relieving medications is not euthanasia. Analgesia that is reviewed and adjusted in a systematic way in response to the resident's assessed need will provide comfort while the underlying progressive process of dying takes its course.

To deny prescribed analgesia is unethical as it will deny "good" (comfort) and it will not cause harm (eg. death).

Working through ethical issues

In end of life care situations when a sense of unease arises, it may be useful to work through the following steps.

What values (ethics) are in play

Try to identify the goals and strategies that are being presented as most important, and the values underpinning these.

Identify the relevant participants

There is no dilemma or feeling of unease unless there are multiple persons involved. Other care staff, the family, the resident and external providers are all potential contributors to differences in care decisions.

Power, powerlessness & process

Having a different view may be one part of the dilemma during decision making, but in addition the decision making about care is not shared equally. Some participants have legal authority. Some participants may influence decisions through other means. Are some participants feeling powerless or unheard? Has a reasonable decision making process been followed?

Situation, intervention, non-action.

It is important to clarify the current situation, the possible interventions (care responses) available (such as inserting tubes or transferring to hospital), and the consequences of not intervening.

Evaluate benefits, burdens and risks.

Has the decision been grounded in fact about best practice, about known risks, with a realistic estimate of benefits for the resident (or their family)? Has all the information been made available in a clear way?

Agree to / accept resolution process

In such a process there needs to be a general willingness that the treatment decision is reasonable (having considered all the above) and that it will be accepted by the participants. For staff this is about professionally supporting the decision regardless of personal views.

Policy / guideline development

Although individual factors are always important, many care issues arising during the end of life period will be similar. The complexities of decision making will be streamlined if clear policies and guidelines are developed in response to ethically difficult experiences.

Discussion and inservice.

To the extent that some ethical discomforts arise from different understandings or knowledge about the real risks and benefits of end of life interventions, sharing and discussing such information will support care providers.

Summary box: Module 8

Aspects of care around the end of life can lead to disagreements amongst care staff, other providers and family.

These differences about what should, or should not, be done are based on particular values.

A process of working through difficult decisions can assist staff providing end of life care.

Module 9 : Quality considerations in end of life care

Learning outcomes

By the end of this section the learner should be able to:

- Recognise the value of reviewing end of life care

The need for continuous quality improvement in health care is well known. The end of life experience of care is a useful place for quality review. However, some factors may work against this. Following a death both the resident and their family effectively disappear, to be replaced by the next admission to the facility or service. The facility and staff move on.

Yet the end of life period has a disproportionate impact on care staff. Care decisions may be more difficult, and a sense of loss will be experienced to various degrees. The risk in not reviewing end of life care is that issues or problems may repeat themselves if not first identified and addressed.



Consider a recent episode of end of life care you were involved in. Did any problems arise around the planning, organisation or delivery of care? Were items available when required? Were providers contactable when needed?



Writing activity

Make a note of any matters you have recalled.

Reviewing the process of providing care at the end of life will help in ensuring that the best possible care is being provided. Problems need to be identified before they can be solved.



Does your facility or service have a standard approach to reviewing end of life care? Locate / identify any document or tool that is used. Would it have allowed the issues you raised above to be identified and addressed?



Consider the Quality Indicators Chart at the end of Appendix 1. Would this tool have allowed your issues or concerns to have been documented?

Summary box: Module 9

Issues can arise around processes and procedures in end of life care provision.

Reviewing end of life care allows concerns to be raised, and problems to be identified and addressed.

Staff perceptions of end of life care are an essential part of the review process.

Central Coast Collaborative Pathway	SURNAME		D.O.B.	
	FIRST NAMES		AGE	SEX
	ADDRESS			
			POSTCODE	
	TELEPHONE		M.R.N.	

(Adapted from the Welsh ICP)

This Pathway is intended as a guide in providing care for the resident and his/her family in the last week of life. This document is placed in the resident's notes upon commencement, and forms part of the medical record. The pathway can be commenced only with the confirmed authorisation of the resident's current VMO, Staff Specialist or General Practitioner.

Each professional is encouraged to exercise their own clinical judgement at all times.

INSTRUCTIONS FOR USE

Place this document in resident's medical record.

Section 1 is completed by an attending Medical Officer as the resident is entered onto the Pathway.

Section 2 is completed by a Registered or Enrolled Nurse.

Section 3 is completed upon the resident's death by the attending Nurse.

Section 4 (Comfort Assessment Chart) is completed regularly by nursing staff, and is kept at the foot of the bed. A new chart is to be used each day.

Section 5 (Optional Quality Indicators Chart) is completed during care and after the resident's death by the attending Nurse and utilised in local quality reviews.

Progress notes are used to record any symptom event or other issue.

MANDATORY CRITERIA FOR COMMENCEMENT

Resident is medically assessed to be dying, with death anticipated within a week;

And a "not for CPR" order is discussed and documented;

And a "not for hospitalisation" order is discussed and documented;

And at least two of the following apply to the resident:

- ❖ Bedbound
- ❖ Semi-Comatose
- ❖ Only able to take sips of fluid
- ❖ No longer able to take tablets

Central Coast Collaborative Pathway	SURNAME		D.O.B.	
	FIRST NAMES		AGE	SEX
	ADDRESS			
			POSTCODE	
	TELEPHONE		M.R.N.	

SECTION 1

This section to be completed and signed by the attending Medical Practitioner (usually the resident's General Practitioner).

(All "No"s to be documented in Progress notes.)

Criteria for commencement of Collaborative Pathway

1. Resident is assessed as dying, death expected within a week. Yes

2. Not for CPR order / Not for hospitalization order has been discussed with and agreed to by resident / carer. Yes

3. At least TWO of the following (tick) :

Bedbound Only able to take sips of water

Semi- Comatose No longer able to take tablets

A. Current medication reviewed and non essentials discontinued Y N

- Appropriate medications converted to subcutaneous route
- Syringe Driver commenced if indicated and available (See Relevant Guidelines)

B. PRN subcutaneous medication ordered as per Guidelines Y N

C. Discontinue inappropriate investigations and observations Y N

- Initiate Comfort Assessment Chart (Section 4)

Current condition and commencement of this Pathway has been discussed with

• Resident Y Unable

• Primary Carer / Other Y Unable

Primary Carer / Other Details:

Name _____ Relationship _____

Contact Phone Number/s _____

Contact Availability At anytime [] Not at night []

Doctors Name

(print) _____ Signature _____ Date _____

Central Coast Collaborative Pathway	SURNAME		D.O.B.	
	FIRST NAMES		AGE	SEX
	ADDRESS			
				POSTCODE
	TELEPHONE		M.R.N.	

SECTION 2

This section to be completed by the attending Registered or Enrolled Nurse.
(All "No"s to be documented in progress notes.)

**Spiritual /Religious /Cultural needs determined
with Resident / Family /Carer and addressed**

Y **N** **N/A**

Special needs and/or rituals related to the dying and post death period identified and documented. Religious / pastoral resources contacted where indicated.

(Document relevant information) _____

**Initial concerns of Resident and /or Family /Carer identified
and addressed**

Y **N** **N/A**

Issues raised relating to impending death and/or bereavement documented

Comfort Planning

Need for single room assessed **Y** **N** Need for special mattress assessed **Y** **N**

Comfort Assessment Chart commenced **Y**

Name (Print) _____ Signature _____ Date _____

SECTION 3 – To be completed by nursing staff post death.

The deceased is cared for in accordance with Local Policy

Y **N**

Resident's Family / carer are kept informed and supported immediately after death

Family/Carer Provided with Bereavement information

Y **N**

(Eg. Palliative Care Bereavement Service details)

SECTION 5 - (Quality Indicators Chart) is finalised after the resident's death by the attending Nurse.

Name (Print) _____ Signature _____ Date _____

Central Coast Comfort Assessment Chart	SURNAME		D.O.B.				
	FIRST NAMES		AGE	SEX			
	ADDRESS						
						POSTCODE	
	TELEPHONE					M.R.N.	
<p>Instructions: Score each box: M for goal Met, U for goal Unmet, NA if Not Applicable DATE: _____ Record unmet goals in progress notes. Note: 4th hourly recommended while symptoms present. If symptom free for 24 hours, less frequent observation may be indicated</p> <div style="text-align: right; border: 1px solid black; padding: 2px; display: inline-block;">Time of Assessment</div>							
SYMPTOMS	GOAL						
PAIN	No evidence of pain (in last 4 hours)						
NAUSEA / VOMITING	No episodes of nausea or vomiting (in last 4 hours)						
RESPIRATORY	No apparent distress or excessive secretions						
AGITATION	No visible restlessness or agitation						
Other							
COMFORT MEASURES	GOAL						
OPTIMAL POSITIONING	Comfortable position maintained						
MOUTH CARE	Mouth / lips clean and moist						
EYE CARE	Eyes are clean and moist						
SKIN CARE	Skin is clean, moisturiser applied to dry areas.						
MICTURITION	Resident is dry and comfortable. Urinary aids used if incontinent / retention.						
BOWEL CARE	Resident is not agitated or distressed due to constipation or diarrhoea.						
SUPPORT	Resident and family / carer supported: Procedures explained; Information about changes provided; New concerns identified and responded to.						
SPIRITUAL / CULTURAL NEEDS	Identified Spiritual / Religious / Cultural needs / rituals are facilitated						
	Nurse's Initials						

Binding Margin – Do Not Write

Collaborative Pathway Quality Indicators Chart

(To be completed at conclusion of Pathway)

Item	Y or N please circle	Problem Description if N	Action Taken / Recommendation
Symptoms managed by guidelines	Y N		
Comfort needs addressed by pathway	Y N		
Spiritual / Cultural / needs addressed by pathway	Y N		
Support needs addressed by pathway	Y N		
Bereavement care facilitated by pathway	Y N		
Other problems that were <u>not</u> addressed by pathway			
Overall death was satisfactory for Patient Family / Carer Staff	Y N Y N Y N		

Internet resources

Central Coast Collaborative Pathway Project.

www.centralcoast.health.nsw.gov.au/pall_care/index.htm

Marie Curie Cancer Care. Liverpool Care Pathway: promoting best practice for care of the dying (UK)

<http://www.lcp-mariecurie.org.uk/>

Australian Pain Society. Pain in Residential Aged Care Facilities – Management Strategies.

<http://www.apsoc.org.au/owner/files/9e2c2n.pdf>

The National Council for Palliative Care. Introductory Guide to End of Life care in Care Homes (UK)

<http://www.ncpc.org.uk/download/publications/GuideToEoLC%20CareHomes.pdf>

(or <http://www.ncpc.org.uk/publications/index.html> and follow the link.)

Palliative Care Australia. Standards for Providing Quality Palliative Care for all Australians

<http://www.pallcare.org.au/Default.aspx?tabid=317> and follow the link

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