Disability Services
Palliative Care
A Self-Learning Package
Acknowledgement: The development of this learning package was kindly supported by the PEPA Program and Southern Adelaide Palliative Service

Confidentiality: For official use only
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Important Contacts

Central Adelaide Palliative Care Service ............ 8161 2351
Northern Palliative Care Team ......................... 8161 2351
Southern Adelaide Palliative Care Service ........... 8275 1732
Palliative Care Council SA ................................ 8291 4137

Other useful numbers for your site:

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Aims and Objectives

Aims
This learning package aims to enhance the knowledge of Disability Staff involved in the care of a person receiving palliative care.

Objectives
It is expected that on completion the individual will:

- Have a greater understanding of palliative care
- Have a better understanding of recognising the deteriorating person and how to respond
- Have a better understanding of communicating with a person who has been given bad news
- Have knowledge of the symptoms a person with palliative care needs may have and how to respond
- Have an greater understanding of how to recognise when a person is entering the terminal phase and how to respond
- Develop skills to communicate and support family members, other clients, colleagues and yourself when a person is dying
- Have a better understanding of community resources that are available.
Introduction

The final stage of life is a very sensitive and significant time for people and their loved ones. The time before, during and following death are subject to a variety of customary practices.

This self-learning package aims to be educative, provide insight into appropriate cultural knowledge and practices, and identify tools that will assist staff in providing culturally and clinically responsive care to people and their families.

Advances in medical technology have contributed to people living longer despite chronic illnesses, degenerative diseases and disabilities. However, questions are raised about how much invasive or aggressive medical attention is necessary or a good thing.

Issues like quality of life, statement of choices about medical procedures and care, values and beliefs, and what makes a ‘good death’, need to be openly discussed before a person becomes critically ill as they are usually less able to participate in making their own decisions at this time.

It is important that these discussions include the person/guardian so that their wishes and choices around advanced directives, ageing in place and palliative care are met.
Definitions

What is palliative care?

The World Health Organisation (2010) defines palliative care as:

An approach that improves the quality-of-life of individuals and their families facing the problems associated with life threatening illness, through the perception and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

A palliative approach

A palliative approach aims to improve the quality-of-life for a person with a life-limiting illness and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs. Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying.

A person who is dying has the right:

- to be treated as a living human being until they die
- to be cared for by those who can maintain a sense of hopefulness; however, changing this might be
- to express feelings and emotions about approaching death in their own way
- to participate in decisions concerning care
- to expect continuing medical and nursing attentions even though ‘cure’ goals are changed to ‘comfort’ goals
- not to die alone, in most cases
- to be as free from pain as possible
- to have questions answered honestly
- not to be deceived
- to have help from and for families in accepting death
- to die as far as possible in peace and dignity
- to retain their individuality and not be judged for decisions which may be contrary to beliefs of others
- to discuss and enlarge their religious and or spiritual experience whatever these may mean to others
- to be cared for by caring, sensitive, knowledgeable people who will attempt to understand their needs and will be able to gain some satisfaction in helping them face death.


**Why is a palliative approach important?**

A palliative approach can:
- reduce distress for individuals and their families/guardians
- reduce transfers to hospital because staff develop skills to manage the palliative care needs of individuals
- help to involve the individuals and their family in decision-making about their care
- encourage open and early discussion about death and dying which helps advance care planning
- provide opportunities for improved control of pain and other symptoms
- allow the individual to be cared for by staff that they know and have developed a rapport with.
When does an individual need a palliative approach?

A palliative approach is not limited to the last weeks or days of life. It is a philosophy of care that may be appropriate many months before an individual actually dies and aims to improve the quality-of-life for people with an eventually terminal condition and their families.

*Michael was a 42 year old man diagnosed with multiple sclerosis, neurofibromatosis, cognitive impairment, and a closed head injury in 1987. He was living in a shared house in community supported accommodation in Disability Services for about three years. He had been admitted to hospital a number of times over the previous year, and was deteriorating in that he was now unable to verbally communicate, move himself, and required assistance to eat and drink a vitamised diet. The Disability Community Nurse liaised with the accommodation manager and the family to make a referral to the local Palliative Care Service for a review of the situation.*

Specialist palliative care

A small number of individuals may experience severe or complex problems as their condition advances. These may be physical symptoms or complex ethical dilemmas, family issues or psychological distress. Specialist palliative care teams do not usually take over the care of individuals but instead can provide advice on complex issues and support the general practitioner and Disability team.

*(The University of Queensland (2011) The Palliative Approach Toolkit: A Palliative Approach in Residential Care)*

**Q1:** What does a ‘palliative approach’ mean to you?
Recognising a Deterioration in a Person’s Health Status

There are a number of indicators that a person’s health status is deteriorating.

Things to look out for:
- swellings or lumps
- clothes not fitting properly due to changes in body shape
- weight loss or gain
- personality changes
- changes in eating habits
- changes in toilet habits
- generally feeling unwell
- tiredness or lethargy
- changes in behaviour
- frequent choking at mealtimes or on saliva
- asking for or requiring more pain relief than usual.

Support staff may be the first people to notice changes in a client’s health and are well placed to report these changes to their manager. The manager will liaise with the registered nurse for clinical advice.

As soon as there is a suspicion of any health change the person will need to visit their general practitioner (GP). It is important that the person has someone familiar to them to accompany them on this visit and can advocate for further investigations and communicate on their behalf, if appropriate.
The GP will make the decision if the person’s health is in decline, if further investigations are required or a palliative approach is appropriate.

All clients within Disability Services will already have Support Plans in place, and possibly Health Care Plans and Health Plans.

An immediate review of the health support arrangements for the person will be required if he/she is now to receive palliative care.

The accommodation manager will use the Health Support Risk Assessment tool in the Direct Health Support of People with a Disability Guideline to do this.

**Q2:** If you notice a deterioration, or are concerned about the person’s health status, what would you do?
Health Support Risk Assessment

(From Direct Health Support of People with a Disability Guideline)

Most clients are likely to fit into the Level 1 or Level 2 areas of health support. For example, a person may have epilepsy, asthma or require support with medication. Agencies will be able to support such individuals with the development of a Health Care Plan, developed by their GP/medical specialist and having support workers trained in key health related areas.

A small number of clients will have health needs that determine that they require additional support at Level 3, which includes the development of a Health Plan by an registered nurse (RN). Staff will need additional training, support and supervision from an RN in order to safely meet the client’s health support needs.

The chart below will assist in determining if the health support needs of clients are Level 3 or whether the advice of an RN is needed to assist in determining the level.

All the ticks need to be in the ‘Yes’ box to proceed without RN advice. Any ‘No’ or ‘Unsure’ ticks indicate that the support needs are Level 2 or 3 and will need RN advice or referral.

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Yes</th>
<th>No (Refer to RN)</th>
<th>Unsure (Note why and seek clarification)</th>
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<tbody>
<tr>
<td>Support needs are clear and documented.</td>
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<tr>
<td>Medical condition is stable and predictable.</td>
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<tr>
<td>Indicators</td>
<td>Yes</td>
<td>No (Refer to RN)</td>
<td>Unsure (Note why and seek clarification)</td>
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<tr>
<td>Support required can be undertaken by a support worker with generic training and competencies.</td>
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<tr>
<td>When undertaking the procedure, support worker is required to exercise judgment only within their generic competency and responsibility.</td>
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<tr>
<td>The supervisor can provide evidence the support worker is deemed competent and able to undertake the task.</td>
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<tr>
<td>The task is generic and non-invasive.</td>
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<tr>
<td>Medical documentation enables the support needs and expected support needs to be clearly understood.</td>
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<tr>
<td>Documentation to support decision making is relevant/current.</td>
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<tr>
<td>There is adequate time available to plan the level of support required.</td>
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What Needs to be Put in Place?

Michael’s parents were very involved and were also his guardians. A Statement of Choices had been completed whereby Michael was not for a peg tube, only basic first aid if choking, not for resuscitation, and his body and brain were to be donated for medical research. His parents did not want him to go to hospital if unwell, and wished for him to be treated at his home.

The Community Nurse in Disability Services noted Michael had deteriorated in his capacity to eat and drink, was unable to swallow his saliva and had significant weight loss. He could not respond verbally when asked how he was feeling.

A case conference was organised with The Specialist Palliative Care Nurse, Medical Officer, family, Accommodation Manager, key support staff and Clinical Practice Consultant from Disability Services to ascertain his status.

A long discussion about advanced care planning occurred, and a letter to his GP was sent with medication recommendations and an offer of support from the Palliative Care Team.

Another case conference was held three months later to clarify issues and decisions were made within palliative care guidelines for Michael. His parent’s ability to provide consent was also clarified with the Guardianship Board to confirm they were able to make medical decisions.

It is important to respect the decisions family make, especially when they clash with your own beliefs and you don’t agree with them personally. Making the decision to accept palliative care often comes after a lot of consideration and years of suffering for the person and their family.
When a person is requiring palliative care, the following are processes that are required to be put in place to support him/her in their home:

- Clarification with the GP that a palliative approach is appropriate
- A case conference organised with the person, their family/guardian, Community Nurse, GP, Palliative Service, accommodation manager(s) and key support staff
- Using the End of Life – Palliative Care Decision-Making Process flowchart to plan the next steps
- Accessing the Palliative Care Resource Manual and the Staff Instruction Resource Manual for community contacts, and the organisation’s processes
- Implementing Health Plans written by the Community Nurse
- Reviewing training needs for staff to support the person
- Developing communication opportunities for the person, family or staff to discuss their concerns, fears or hopes.

Q3: Why is it important to have a case conference for a person who is palliative?
End of Life – Palliative Care
Decision-Making Process

Palliative care suggested by family, GP or other
This is a level 3 health support task and the registered nurse (RN) must be involved

Advanced Care Planning commenced or reviewed by doctor and RN, with family/guardian and service unit manager (SUM), referring to Advanced Care Planning using the
Respecting Patient Choices Program Standard and Statement of Choices form

SUM coordinates palliative care decision-making process and organises a team meeting discussion with RN and relevant parties including family/guardian and local palliative care service

Palliative care implemented

Continue ongoing treatment or review

SUM communicates decision to family, staff ASSIST, etc

RN completes Palliative Care Health Plans – files old plans in client records

SUM and RN meet with relevant staff to discuss the decision and any supports that are required

RN assesses client comfort and care needs

SUM/family organises spiritual support

SUM organises emotional support

RN develops Health Plan under domains (eg pain management, skin care)

Chaplain/religious/other

Individual counselling for client/family/staff

SUM with RN arranges staff education/training/CBA

External resources

Employee Assistance Program/chaplain

RN liaises with regional palliative care services

Volunteers arranged through SUM and volunteer manager/church and appointed to client

Staff meetings for debriefing
What do I Say? – Communicating about Illness and Dying

Amongst the most traumatic and stressful situations we have to face in life are illness, disability and mortality. The way that individuals react to situations depends on a number of factors:

- Life experience
- Mental capacity
- Personality
- Culture
- Beliefs
- Values
- Attitudes
- Emotional stability.

When diagnosed with a terminal illness initial reactions are often shock and disbelief. Gradually, over time, most will begin to accept their situation and with their families and accommodation staff many show an impressive ability to adapt to the changes necessary in their lifestyle.

Many who have insight into their disease will adapt to their deterioration and increasing dependence with remarkable courage.

Regardless of the strength of the adaptation, we need to encourage all individuals and families to maintain normality and their interests as long as possible.

Additionally, it may be helpful for the individual to talk to someone outside of the immediate family. A support worker, family member, friend or the local clergy may provide the opportunity for the individual to talk.
Some individuals with disability are very articulate and can communicate thoughts and feelings in a very profound and meaningful way. However, other people may struggle to communicate without the use of communication tools or alternative communication systems. It is important to determine the person’s:

- understanding of serious illness, death and dying
- cognitive ability
- communication style
- concept of time.

This is important when considering whether and when it is appropriate to open a supportive discussion about their illness and wishes for the end of life. Avoid the use of abstract language in discussions about dying (eg talk about ‘dying’ rather than ‘passing away’).

There is a danger of a ‘conspiracy of silence’ to exist where family, friends and staff all know that the person has a terminal illness and poor prognosis; however, they will not talk to them about it.

The intent is to protect the person from the knowledge. This has the potential to increase distress.

There is a need to assess the individuals understanding of their illness and answer questions as directly, honestly and simply as you can.

**Q4:** How could a person react to receiving bad news?

**Q5:** What would you do to support them?
Symptom Management

Health Plans developed for Michael were implemented for skin and mouth care, diet and fluid monitoring, bowel management and medication management as per Direct Health Support of People with a Disability Policy and Guideline. Staff training and competency-based assessments occurred as Michael is now requiring support for Level 3 health tasks. Time was spent with staff developing the knowledge and skills in what Palliative Care is about, symptoms to expect and terminal care planning for Michael.

As identified in the case study, there are many symptoms that a person may experience including:

- Emotional difficulties including depression and anxiety
- Difficulty in swallowing and choking
- Pain and discomfort
- Pressure area care
- Incontinence
- Constipation
- Mouth ulcers/sores.

If any of these symptoms occur follow the Health Plan and contact the accommodation manager and registered nurse.

**Q6:** If you noticed a person experiencing any symptoms, what would you do?
Recognising Dying

Identifying when a person is moving into the terminal phase is not easy. Goals of care will focus on their physical, emotional, cultural and spiritual needs. Support for families, including bereavement care, is of paramount importance.

A person may experience some or all of the following when approaching death:

- Rapid day-to-day deterioration that is not reversible
- Becoming more drowsy with lapses into unconsciousness
- Increasing loss of ability to swallow
- Refusing or unable to take food, fluids or oral medications
- Irreversible weight loss
- Profound weakness
- Changes in breathing patterns.

If any of these signs and symptoms occur follow the Health Plan and contact the accommodation manager and registered nurse.

*Three months later the Disability Services Community Clinical Practice Consultant contacted the Specialist Palliative Care Team as Michael was physically deteriorating and choking on sputum, which required action to be taken, and a review of his Health Plan. Three weeks later Michael experienced a respiratory event. An ambulance was called as he had a rapid pulse and high fever. It was felt he was developing an aspiration pneumonia. His family were contacted who wished for him to be transferred to the hospice for symptom management and possible terminal care. A bed was available, so he was transferred by ambulance and admitted on the same day.*
He quickly deteriorated over the next few days and was provided with care aimed at best comfort. Michael’s family stayed at his side during this time. Michael’s friends, and support workers, were able to visit him at the hospice during this time to say goodbye.

Michael died peacefully with his family around him.

Whereas palliative care may take place over many months or even years, terminal care is the care focused on the final days or weeks of life. At this point care decisions may need to be reviewed more frequently.

**Q7:** How would you recognise the person is entering the terminal phase?

**Q8:** What would you do if a person was entering the terminal phase?
Place of Care

A person has the right to choose their place of death and this should be respected and supported as much as possible.

Supporting a person with disability to die at home can have its challenges but also can be a realistic option, and staff should consider the following issues.

Advantages

- The person is in a familiar setting amongst others and staff who know them.
- Better able to meet the needs/wellbeing of the person outside of hospital routines.
- Better access for staff, other people/friends and family, allowing goodbyes to occur in the person’s own time.
- The person is not alone – being cared for at the residence may be a good way for the person not to be alone.

Challenges

- There may be an increased use of casual staff in the residence, either in caring for the person or the other clients.
- There may be a negative impact on the other clients and staff. It can be difficult to predict clients and staff reactions to the end-of-life care of a client. Palliative care services will be able to advise on support strategies.
What should be in place?

- The commitment of staff to provide care
- Access to an area that can be organised to meet the comfort needs of the clients, for example, private space for visitors, temperature controlled
- Access to aides/equipment to assist with care and transfer requirements
- Links with, and access to, health/specialist palliative care including 24 hour support where required
- Support for staff, for example, meetings, debriefing and personal support, access to secondary consultation
- Access to symptom control and pain relief medication
- Staff who are able to manage any medical equipment required
- Plans of care and a means to reassess the at-home arrangement.

(Disability Residential Services Palliative Care Guide, Victorian Government Initiative 2010)

Q9: How would you support the person to stay at home to die if they choose to?
Managing Loss and Grief

As the person moves into their terminal stage, it is important that everyone involved is communicating around how best to support and care for the person who is dying and their family.

Staff will also feel grief as they have developed relationships with the person; however, their own personal feelings must not influence or overshadow the person’s, and their families’, grieving.

Staff in community homes seldom have formal training or experience in care for a dying person. It is important, therefore, for staff to be able to look after themselves during this time. Staff can access support from their managers through the Employment Assistance Program (EAP).

People have many different ways of managing grief and loss, based on their cultural, religious or spiritual beliefs. There are recognised stages of grief and loss that can include denial, depression, guilt, anger, and finally acceptance.

When a person dies in their home, be that in the community or a facility, it is important to understand and acknowledge that anyone connected to the person’s support and care will feel grief at their passing.

The grief felt by other people who lived with that person must not be underestimated, as complex grief reactions can develop.
The following are some methods of managing your and other’s grief:

- Make sure all involved staff and people who lived with that person are aware of the death.
- Acknowledge the death of the person with other people who lived with that person.
- Acknowledge the grief reactions of your and other’s grief.
- Reminisce with the other people in the house/facility (eg use photos to celebrate their life).
- Help other people who lived with the person to understand the death of the person.
- Allow time for staff and people who lived with that person, to come to terms with their loss.
- Be aware that the expression of grief may be unrestrained and behaviour may change.
- Participation in the funeral and memorial services to pay respect are helpful.
- Talk to your colleagues and manager about how you are feeling.
- Participate in a house/facility meeting to debrief.
- Seek support (eg counselling).

**Q10:** How could you support others after a person has died?

**Q11:** Where can you access support for yourself if required?
Reference List and Resources

Operational Documents

Direct Health Support of People with a Disability Policy

Direct Health Support of People with a Disability Guideline

Palliative Care Resource Manual

Publications


The Palliative Approach Toolkit, The University of Queensland, *Comprehensive Evidence Based Palliative Approach in Residential Aged Care (CEBPARAC)*

Victorian Government Initiative, *Disability Residential Services Palliative Care Guide*, 2010

Websites

The following websites were all last viewed 19 March 2013.

Palliative Care Council of South Australia, [www.pallcare.asn.au](http://www.pallcare.asn.au)

*Living and Dying with Dignity*, [www.mencap.org.uk](http://www.mencap.org.uk)

*National End of Life Care Programme*, [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

*Palliative Care for those with Intellectual Disability or Acquired Brain Injury*, [www.healthynt.nt.gov.au](http://www.healthynt.nt.gov.au)

World Health Organisation, Definition of Palliative Care, [www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/)

Answers to Questions

Q1: A palliative approach aims to improve the quality-of-life for a person with a life-limiting illness and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs. Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying.

Q2: As soon as there is a suspicion of any health change the person will need to visit their general practitioner (GP). The GP will make the decision if the person’s health is in decline, if further investigations are required or a palliative approach is appropriate. An immediate review of the health support arrangements for the person will be required if he/she is now to receive palliative care. The accommodation manager will use the Health Support Risk Assessment tool in the Direct Health Support of People with a Disability Guideline to do this.

Q3: For staff to be able to best support clients in their own home, we ensure that their needs are met and that the client, family and staff are aware of these needs. We all clearly communicate and follow processes to deliver palliative care to the person.

Q4: They may react with shock and disbelief. Gradually, over time, most will begin to accept their situation and with their families and accommodation staff many show an impressive ability to adapt to the changes necessary in their lifestyle.
Q5: Regardless of the strength of the adaptation, we need to encourage all individuals and families to maintain normality and their interests as long as possible. Additionally, it may be helpful for the individual to talk to someone outside of the immediate family. A support worker, family member, friend or the local clergy may provide the opportunity for the individual to talk. There is a need to assess the individuals understanding of their illness and answer questions as directly, honestly and simply as you can.

Q6: If any of symptoms occur follow the Health Plan and contact the accommodation manager and registered nurse.

Q7: A person may experience some or all of the following when approaching death:

- Rapid day to day deterioration that is not reversible
- Becoming more drowsy with lapses into unconsciousness
- Increasing loss of ability to swallow
- Refusing or unable to take food, fluids or oral medications
- Irreversible weight loss
- Profound weakness
- Changes in breathing patterns.

Q8: If you thought a person was entering the terminal phase you would follow the Health Plan and contact the accommodation manager and registered nurse.
**Q9:** Staff can assist by respecting the person’s wishes about where they want to stay. There will be challenges but things that staff can do include:

- Being supportive to the client, their family and each other
- Being involved in discussions about plans of care and following these
- Reporting any changes in the person’s health needs to the manager
- Attending training.

**Q10:** We all react differently when someone dies. There are recognised stages of grief and loss that we need to be aware of at this time. Staff could support others by acknowledging the feelings of others, being aware of changes in behaviour, participating in memorial services, talking to others about your feelings.

**Q11:** If staff require support they can:

- Talk to their manager about how they are feeling.
- Access the [Employee Assistance Program](#) if they wish to do so, either independently or through their manager.
- Attend a debriefing meeting.