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A palliative approach for people accessing the service

For the person accessing services, a palliative approach begins when there is a change in the goals of their care from curative (symptom control and supportive care) to end-of-life care due to a life-limiting illness. For many people with life-limiting illnesses, the transition from curative treatment to palliative care is gradual.

As a palliative care team member, you should understand when a person is moving from curative care to a palliative approach. Recognising this change in the type of care required by the person is very important, as it gives you an opportunity to provide tailored support for them, their family and carers. You must also ensure that all stakeholders fully understand the shift in treatment from curative care to palliative care and the impact this may have.



Where palliative care is provided

Palliative care services are provided in a range of settings, listed below. People who are dying must be able to move freely between these places to meet their medical care and support needs. Palliative care is usually best provided in close proximity to the client's local environment and community.

Wherever possible, palliative care is provided in the environment of the person who is accessing the service's choice. In the course of their illness, some people may receive palliative care in all three of the possible settings, depending on their needs.

A significant proportion of anticipated deaths still occur in hospitals and many people are identified as needing palliative care while in a hospital. In many cases, the person prefers to return home in the final stages of their lives, to die with dignity in familiar surroundings.

The three possible settings for palliative care are listed here.

Settings for providing palliative care

- ▶ Community settings, such as an aged or supported care facility or the person's home
- ▶ Purpose-built hospices
- ▶ Designated palliative care beds in hospitals, which are in-patient beds used specifically for palliative care people

Information strategies

People with palliative care needs or their carer/s may tell you they are having trouble with something. They may ask you how they can get help with something. You may be able to assist them through your own service. If not, you need to inform them of where they can obtain further information and support. You may already know of other services that can help or you may need to ask your supervisor.

Here are some strategies for informing people with support needs.

Information strategies

- ▶ Print brochures in other languages.
- ▶ Print material in large print.
- ▶ Record material onto a CD.
- ▶ Use an interpreter.
- ▶ Explain the information in person.
- ▶ Re-write the information so it is easy to understand.
- ▶ Ask questions to ensure the information is understood.
- ▶ Provide information more than once.
- ▶ Answer questions.

Communication and the team

Effective communication with people accessing services and other members of the palliative care team is essential. The team should conduct regular meetings to ensure everyone is aware of the person's current situation and the care provided. This helps reduce any misunderstandings and disagreements. These meetings should also involve the person, their family members and carers, where possible, to allow them to receive current information about the person's status and an opportunity to voice their concerns.

Consider the following to help develop effective communication skills.

Question

Ask the person who they want involved in their support and the level of involvement. Be sensitive to who is considered to be immediate family and next of kin, as friends may play the role of relatives for some people.

Clarify

Clarify who the decision-makers are within the family and who you should share information with; for example, the person, family members or a community representative such as a community elder or religious leader.

Jargon

1D Demonstrate respect and include the family and carer as an integral part of the care team

It is likely that the person accessing palliative care will also be receiving support from others. This can include service providers, family members, neighbours, church groups and people in the person’s networks. It is important that supports are well coordinated and that all of those providing support, work together to ensure the person receives the best care possible. The person’s personal care support plan or assessment information will have the information about the level of support required. You need to be clear about your responsibilities and who is responsible for additional support and services.

Here is further information explaining a coordinated approach.

<p>Family or neighbours</p>	<p>Service providers</p>
<p>The person may have a spouse, family member or a primary carer who lives with them, or visits and provides some support. They may have lived in the area for many years and have a relationship with a neighbour who also pops in to assist where they can.</p>	<p>Other services may provide a range of support. For example, district nursing might attend to dress wounds; home support services might come once a week to do some house work; delivered meals might come from Monday to Friday.</p>
<p>Networks</p>	<p>Community programs</p>
<p>The person may have people who pop in to assist them from time to time, who have been a part of their network for many years. For example, RSL members, people from the same church, ex-sporting or service groups.</p>	<p>Some people might attend or participate in a range of activities in the community. They may have either an informal support person such as a friend or a formal support person who is paid to attend with them.</p>

The family and carer: an integral part of the care team

When a person is receiving palliative care there must be a coordinated team effort between healthcare professionals, palliative care workers, the person, family members and carers. In many instances, the palliative care worker spends as much time with the carer as they do with the person.

2A Encourage the person, carers and family members and/or significant others to share information

The person accessing the service and the people who are closest to them are the ones who best understand the person's needs and preferences. They should be encouraged to share all the information they have to ensure the person's care plan remains current.

Having a supportive network of family and friends is an important part of coping with a life-limiting illness. However, family members and carers may also require support as they deal with their grief and understanding of the situation. It is your job to provide the support they need.



Share information

A key responsibility for a palliative care worker is to build a good working relationship with a person accessing the service's unit of care, so information is willingly shared when the person's needs, preferences or condition changes. This ensures the best and most appropriate care is provided. To do this, the palliative care worker should establish and maintain a supportive environment that is comfortable and non-threatening, and where people are willing to listen and share ideas.

People are more likely to share information if they know they will be listened to and their opinions acted upon. It may be difficult having conversations about prognosis and end-of-life decisions with people who have life-limiting illnesses and their families. Some families may be unable or unwilling to share information and provide support; it may be against their culture or there may be family disputes that have not been settled. Ask your supervisor for guidance when communicating with these people.

Effective communication about end-of-life issues is a vital skill for healthcare professionals caring for people with progressive life-limiting illnesses and when dealing with their families and carers. Some of the valued qualities of communication are honesty, empathy and a willingness to talk about end-of-life concerns. Honest and open communication between the palliative care team and the person can calm the person, increase the person's satisfaction and assist them to make decisions and plan for the future.

Examples of organisational mechanisms for encouraging sharing of information include:

- ▶ making sure family members know they can telephone a team member whenever they need to
- ▶ organising a family conference to facilitate support and information exchange and to help reduce loneliness, loss and social isolation
- ▶ working with an advocate if a family is unwilling to share information and provide supports.

Supporting a person's spiritual needs

- ▶ Allow the person to guide all spiritual interventions.
- ▶ Provide a supportive presence and avoid judgment.
- ▶ Coordinate spiritual services and people; for example, arrange access to chaplains or pastoral care workers, family, carers and friends as requested by the person.
- ▶ Ensure access to spiritual activities such as prayer times, Bible study and worship ceremonies.
- ▶ Obtain requested items for spiritual practice such as books, rosaries, statues.
- ▶ Avoid interrupting a person during spiritual activities.
- ▶ Help people accessing the service to celebrate specific religious events such as Ramadan, Good Friday or Rosh Hashanah.
- ▶ Encourage any pre-death rituals the client may wish to follow.
- ▶ Follow spiritual beliefs in regard to medical treatment; for example, some beliefs may forbid a blood transfusion.

Learn about other cultures

Understanding other cultures, what culture means to a dying person and how cultural issues impact palliative care are essential skills of a palliative care worker.

Many people have limited knowledge of other cultures and customs. If this is the case, a worker should acknowledge this and seek to learn more. This ensures workers respect the cultural beliefs of the people they are supporting and don't cause offence. Palliative care workers must be sensitive of the language and words they use when dealing with culturally diverse people.

Information about other cultures may be available from family members and from pamphlets and brochures published by cultural groups. Remember, these are general guidelines and everyone is different, so ensure the specific needs of each person and their family are understood.



Respect cultural choices

Australia is made up of many cultural groups; the diversity of customs, rituals and values from other cultures adds richness to our community. Palliative care workers must ensure they are sensitive to, and respect, customs that are different from their own. They must understand the concept of death and dying in other cultures and know how these cultures deal with this process. The concept of family may also mean different things to different cultures.

Cultural beliefs provide a structured pattern of behaviour and may also provide comfort. These beliefs are very important at the time of death, when people must cope with strong feelings of loss and confront their own mortality (death). At their initial

Written in error

No alteration and correction of records is to render information in the records illegible. An original incorrect entry must remain readable. Do not overwrite incorrect entries and do not use correction fluid. An accepted method of correction is to draw a line through the incorrect entry or 'strikethrough' text in electronic records; document 'written in error', followed by the author's printed name, signature, designation and date/time of correction. For electronic records the history of audited changes must be retained and the replacement note linked to the note flagged as 'written in error'. This provides the viewer with both the erroneous record and the corrected record.

Example**Consider culture when caring for a person accessing palliative care services****Greek culture**

- ▶ Family, friends and relatives play a very important role in the care of a dying person within the Greek culture. Therefore, the home is preferred to the hospital as the place of treatment.
- ▶ The wife of a dying husband should be directly involved in the care of her husband, as this fulfils her sense of duty and obligation.
- ▶ Many Greek families, relatives and friends may wish to protect the dying person by preventing them from knowing their diagnosis and prognosis. They believe the person dying may give up hope and lose the will to fight.
- ▶ Terms such as 'that terrible illness' or the 'situation' may be used to avoid directly speaking about specific conditions.
- ▶ In the Greek culture, it is acceptable to display strong emotional reactions.
- ▶ For some people there is a strong fear of using morphine as it is associated with death.
- ▶ The role of the church is very important. The Greek Orthodox Church guides the behaviour of people in bereavement and certain rituals and beliefs that must be followed. The body is considered to be highly sacred. Practices include:
 - clothing the body in a white sheet under attire
 - holding a vigil in the funeral parlour where the body is placed facing east
 - after the funeral service, the body is buried as cremation is not permitted
 - a memorial service is held after the funeral and further services are held on the 9th and 40th day and the 3rd, 6th, 9th and 12th month after death
 - candles are lit during services to symbolise the celebration of life and eternal faith
 - people attending the funeral and memorial services traditionally wear black.



(Adapted with permission of the Palliative Care Council of South Australia Inc., <http://www.pallcare.asn.au/>)

2E Use effective communication skills to provide emotional support and empathy

Providing emotional support and empathy to people accessing the service, their families and carers is a key responsibility for those working with people who are at the end of their lives or have life-limiting illnesses. This means you must listen to what the person, their family members and carers say, acknowledge the impact the illness is having on those involved and provide the appropriate support. In some cases, you may only need to be there to listen; at other times you may need to provide information.

Below are the things you need to consider when supporting family members and carers who care for a person who is dying.

Respect feelings

It is important to remember that as well as providing support to the person who is facing death, the needs and feelings of family members and carers are crucial. These people play an important part in the overall care of the person and also need support – especially if this is their first experience of a palliative approach or of an impending death. Family members and carers anticipating the loss of a significant relationship often describe this period as like being on an emotional rollercoaster. Many and varied emotions may be experienced. The anticipated loss of a loved one may lead to feelings of guilt, anger, frustration, distress or family conflict. Do not assume that a person's family is always supportive. There may be conflicts within the family; for example, regarding care.

Identify needs

People in a palliative environment have a range of emotional needs including the need to:

- ▶ grieve
- ▶ hope
- ▶ express their feelings freely
- ▶ maintain their self-esteem and dignity
- ▶ come to terms with fear, uncertainty and impending loss.

Listen to feelings

An important part of a palliative care worker's job is to listen.

Always let the person finish what they are saying before you respond. Never try to change the subject, make a joke or respond with comments such as 'It's all for the best' or 'At least they won't suffer for long'. It is important to come to terms with your own beliefs and attitudes regarding death and dying so you are able to provide calm and rational support.

Effective communication strategies

Effective communication with people accessing the service and other members of the palliative care team is essential. The team should conduct regular meetings to ensure everyone is aware of the person's current situation and the care provided. This

Below are the steps to follow if you identify symptoms of pain.

Recognise the type of pain a person may experience

- ▶ Information relating to person's pain is detailed in the care plan and through the instructions you receive from your supervisor. It is important for you to understand the meanings of any medical words used in the care plan or by the supervisor.
- ▶ This will assist you to be prepared for the pain you may observe.

Monitor and identify the symptoms a person is experiencing

- ▶ Sometimes it is easy to make your own observations regarding a person's pain; for example, you may see the person holding a part of their body tightly, groaning or constantly changing position in an effort to become comfortable. A person may experience pain only at the end of the day or after they have taken medication.
- ▶ Always record these observations, especially as person may not always tell you if they are in pain.

Ask the person to describe the pain

- ▶ Ask the person to describe the pain. To better understand the pain a person is experiencing, ask them to describe the type of pain they are having, how bad it is, when it starts, how long it lasts and where it is located. For example, ask the following:
 - Where is the pain located?
 - Does it spread from one area to another or is it in the one place?
 - How does the pain feel; for example, is it throbbing, piercing, sharp, dull?
 - Is the pain ongoing or does it stop and start?
 - Does the pain occur when you are lying down or sitting up?
 - Does the pain get worse when you are walking?
- ▶ If the person has difficulty communicating, use pictures or a scale where one indicates slight pain and 10 indicates severe pain. You can use a line with numbers or words attached, where the person moves a slide to the number or area matching the severity of their pain. You may require the services of an interpreter.
- ▶ Some workplaces have brochures you can give to people, written in a variety of languages, which describe the pain and what may be done to manage it. Be familiar with the types of resources available to you.

Listen to what the person says about their pain

- ▶ Always listen carefully to how a person describes their pain. They may use words such as intolerable, unbearable or annoying. Some people may deny they are in pain and use words such as discomfort or uncomfortable. You must follow up immediately if a person says they are in pain, by notifying your supervisor or another member of the care team.

Identify any changes in a person's pain

- ▶ Constantly monitor the person's behaviour and what they tell you, so you can determine if there are any changes in the type, location and severity of pain they are experiencing.
- ▶ Ensure you document any changes and inform others as soon as there is a change.

Fatigue

Fatigue is physical and/or mental exhaustion that can be caused by stress, medication, overworking, or mental or physical illness or disease. The person accessing the service may have more than one reason for fatigue to occur and the appropriate team member needs to assess and implement care strategies to address any reversible causes. It is important that the personal care worker reports symptoms of fatigue to the supervisor and documents this in the case files.

Anorexia

Anorexia is the loss of appetite that results in weight loss. This can be distressing for personal care workers, families and carers. It can be an indication that the person is approaching the end of life. The personal care worker should report anorexia to the supervisor or relevant palliative care team member for assessment. Some causes of anorexia are reversible.



Cachexia is a wasting syndrome and is caused by loss of muscle and fat, often due to chronic illness. People accessing the services may develop this and simultaneously experience loss of function, requiring full assistance with activities of daily living.

Reasons a person may become anorexic include:

- ▶ increased disease
- ▶ side effect of treatment
- ▶ side effect of medicines
- ▶ nausea
- ▶ constipation
- ▶ depression
- ▶ fatigue
- ▶ dry mouth.

Shortness of breath

Shortness of breath is often referred to as dyspnoea. Dyspnoea can be a result of both physical and psychological causes. If a person accessing the services has shortness of breath, the personal care worker should immediately report this to the supervisor and document the episode in the case files. The person may be ordered medication or oxygen by the doctor to treat dyspnoea. Other measures that can be taken by the personal care worker is to support the person with activities of daily living to avoid exertion, assist in positioning the person to provide comfort and monitoring oxygen delivery as per orders.



Dyspnoea can occur in a person due to:

- ▶ tumours in the airway
- ▶ coughing/wheezing
- ▶ pneumonia
- ▶ anaemia
- ▶ low blood oxygen levels
- ▶ fear
- ▶ panic
- ▶ anxiety.

Pain management

A person's pain management may involve:

- ▶ non-opioids, such as paracetamol or aspirin, which are delivered orally (by mouth), unless this causes ongoing nausea and vomiting or the person has difficulty swallowing
- ▶ opioids, such as Panadeine Forte, orally for moderate high-level pain
- ▶ opioids, such as codeine or morphine, orally for high-level pain
- ▶ regular analgesic medication (for example, every four hours) to prevent pain returning
- ▶ drugs, such as anti-depressants, to help the client remain calm or steroids to reduce any swelling.

Person responsible

- ▶ A registered nurse (division 1) must administer morphine regularly via a drip bag at the appropriate rate, give prescribed anti-depressant medication to the client in the morning and administer sedatives for swelling.
- ▶ Carers/support workers may apply hot and cold packs and/or aromatherapy (the carer's role in administering alternative therapies will vary depending on the training requirements of the therapy).
- ▶ A physiotherapist may assess and treat musculoskeletal disorders; however, clients may be assisted with ongoing exercises by carers/support workers.
- ▶ Carers/support workers may use music therapy; that is, play the client's favourite music as a means to calm them.
- ▶ Carers/support workers may give clients a daily hand massage with essential oils.
- ▶ A diversional therapist may run a daily meditation session for clients.

Example

Pain-relief directives in the care plan

Care plan

Client name: Mr Roy McDougall

Birth date: 03/09/1934

Room: 3B

Worker name: Julie Rinaldi

Assessment date: 04/08/2016



Diagnosis:

Early stage dementia, significant hearing loss, reduced blood supply to the heart caused by coronary artery disease, prone to deep-vein thrombosis (DVT) in legs, uses a four-wheeled walking frame following surgery for fractured hip. Has developed a pressure area post-surgery, with necrotic tissue, on right leg. The foot is also heavily infected.

People should not receive pain relief until cause is determined

Appropriate response

- ▶ One of the aims of a palliative approach is to provide relief and comfort to the person when a cure is no longer possible. It is an important responsibility for the whole palliative care team to understand and implement strategies to promote comfort as a response to pain after an assessment of the person has been conducted.

Person to refer to for clarification

- ▶ Nurse, palliative care team leader or supervisor

The person may become addicted to pain-relief medication

Appropriate response

- ▶ Drug addiction is often associated with people misusing drugs. However, addiction is not an issue when opioids are used correctly to relieve pain. I will organise for the doctor to come to see you later today to discuss any concerns you may have.

Person to refer to for clarification

- ▶ Doctor

Strong analgesics may shorten a person's life

Appropriate response

- ▶ I'll explain your concerns about the safety and effectiveness of strong analgesics to your doctor and get back to you.

Person to refer to for clarification

- ▶ Doctor

Pain management alone is not palliative care

Appropriate response

- ▶ Yes, pain management alone is not palliative care. Palliative care enhances the person's quality of life by treating pain and physical, psychological, social and spiritual problems in a holistic manner.

Person to refer to for clarification

- ▶ Nurse, palliative care team leader or supervisor

The person is too drowsy to communicate with family members

Appropriate response

- ▶ Yes, some pain-relief medication may cause the person to feel very tired and they may not be able to communicate with you. They may even fall asleep.

Person to refer to for clarification

- ▶ Nurse, palliative care team leader or supervisor

5A Identify changes that have been made and reviewed in the care plan

It is one of the main responsibilities for the personal care worker to review and update the person's care plan. The care plan needs to reflect any changes in care delivery, in line with changes in the person's condition and wishes.

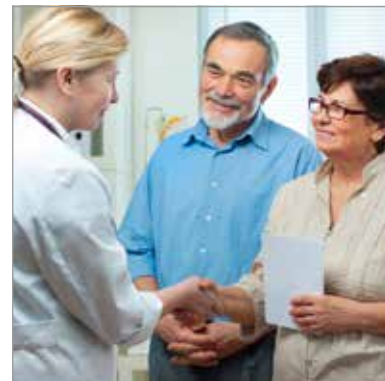
In many facilities it is a requirement of the work role that care plans are updated on a regular basis. This generally occurs at the end of the shift in readiness for the next shift to review. The care plan is a dynamic document that reflects the person's condition and is a legal document.

By regularly checking the care plan, a personal care worker can be confident that the care delivered to a person is the most appropriate, respects the person's wishes and is responsive to the person's needs.

If a change has occurred in the care plan that the personal care worker is not confident in delivering or unsure whether this falls within their scope of practice, the matter should be referred to the supervisor for clarification. The care plan should be checked at the start of the shift and regularly checked over the progression of the shift.

Changes to the care plan and implementation of care

The care plan will change as the person's condition changes. When signs of imminent death are present there are often frequent changes to the care delivery to meet the changing needs of the person. The end-of-life care plans often have directions and planning that encourage good communication between all members of the palliative care team and family. The individualised care plan allows the person's care needs and those of their family to be met. It promotes co-ordination among the multi-disciplinary team to provide high-quality care. The person is able to decide on the setting of end-of-life care and delivery of care can occur in the setting chosen. The care plan will include details of services that are being used by the person and this can change depending on the person's care needs and those of the family/carer.



5C Provide care in accordance with the person's preferences and culture

Meeting the person's wishes becomes even more important as they enter the end-of-life phase, even if they are incapable of knowing or understanding what is happening to them. Instructions in the care plan and advance care directives regarding the person's preferences must be understood and followed. These may include:

- ▶ who they want to see
- ▶ the need to be touched
- ▶ rituals they want to follow such as praying
- ▶ the need to be left alone
- ▶ the need to be surrounded by relatives and friends
- ▶ being spoken to in their own language
- ▶ how they want their funeral to be conducted.



Changes in views and preferences

The circumstances of a terminally ill person may change rapidly, so the team must review the care plan with family members, carers and others to identify the person's preferences and whether they are current. Services may need to be modified; for example, if a person has been taking part in social activities but is unable to anymore, the team should determine ways that social interaction can still take place. They may encourage friends to visit and bring books to talk about or music to play. They may be encouraged to talk about the football. As the person moves towards death, they may experience stronger spiritual, religious and cultural views. Any changes should be recorded in the person's care plan.

A person accessing the service may:

- ▶ request more visits from their religious representative
- ▶ change their mind about cremation and want a burial instead
- ▶ decide to refuse treatment in accordance with their religious beliefs
- ▶ want a different pain relief treatment
- ▶ want to return home.

Example

Support family members to be involved

Elizabeth consistently visits her sister, Bea, for several hours each day. She is usually asked to leave the bedside when the palliative care team is in attendance. One day, Annie, a palliative care worker, asks Elizabeth if she would like to assist with Bea's care and if there is anything she would like to do for Bea. Elizabeth says she would just like to help make Bea comfortable. 'I could even wash her. When I was about seven years old and Bea was 16, I was very ill with a high fever. I remember Bea sponging me and how it seemed at the time that she helped save my life. I know I can't do much for her now that she's dying but I'd like to repay her if I can.'

5F Provide emotional support to other people, carers and families when a death occurs

When a person dies, everyone involved in their care may experience feelings of loss and grief. Different people will react in different ways. You need to recognise their emotional needs and provide support when a death has occurred.

After death has occurred, the bereaved individual typically feels much more than physical loss. The deceased person may have played many roles in their life; for example, a spouse may have been a person's lover, best friend, confidante, social partner, housemate, travelling companion, business associate, career supporter and housekeeper. With death, the bereaved individual loses someone who may have filled all these roles and who met those needs. In addition, they lose all the feelings, thoughts, hopes, wishes, dreams, assumptions, expectations and beliefs they shared with the loved one. In some cases, family members may not have resolved issues before the death.

Your role is to offer practical comfort measures to manage end-of-life symptoms and to know what to do when a person accessing the service dies.

Here is the normal range of responses to death.

Emotional reactions

- ▶ Shock
- ▶ Tearfulness
- ▶ Making no sense when they speak
- ▶ Fear
- ▶ Anger
- ▶ Guilt
- ▶ Detachment
- ▶ Helplessness
- ▶ Feeling free
- ▶ Relief

Physical reactions

- ▶ Hollowness in the stomach
- ▶ Tightness in the chest and throat
- ▶ Over-sensitivity to noise
- ▶ A dry mouth
- ▶ A sense of unreality
- ▶ Lack of breath
- ▶ Muscle weakness
- ▶ Fatigue or lack of energy

Mental reactions

- ▶ Disbelief
- ▶ Confusion
- ▶ Preoccupation
- ▶ A sense of the dead person's presence
- ▶ Hallucinations

Practice task 24

1. List and explain the five stages of grief that the person and/or families go through in palliative care.

2. How can a personal care worker support other people after a death has occurred in a facility?

[Click to complete Practice task 24](#)

Summary

1. Palliative care workers must follow the care plan and any instructions they have been given regarding a person's care.
2. It is very important to regularly review a person's care plan, making adjustments and ensuring all workers are aware of any changes.
3. A key responsibility for those involved in palliative care is to ensure that information is regularly shared between all members of the team, including the person, their family members and carers; and that people's concerns and fears are listened to and they are made to feel their contribution is valuable.
4. The circumstances of a terminally ill person may change rapidly, so the team must review the care plan with family members, carers and others to identify the person's preferences and whether they are current.
5. In the face of a progressive illness or the ageing process, the meaning of dignity may change over time.
6. It is important to understand that people, including carers, may react in different ways and to recognise their emotional needs and provide support when a death has occurred.



Topic 6

In this topic you will learn how to:

- 6A Follow organisational policies and procedures when managing emotional responses and ethical issues**

- 6B Identify and reflect on your own emotional responses to death and dying**

- 6C Discuss ethical issues or concerns with the appropriate person**

- 6D Identify and implement self-care strategies to address the potential impact of your personal responses**

- 6E Access bereavement care and support of other team members**

Manage your own emotional responses and ethical issues

Caring for people at the end of their lives can be exhausting because people working in palliative care constantly provide support to others, work in situations where suffering and distress are common and must deal with ethical issues. Palliative care workers need to know how to deal with their own reactions and responses to people accessing services who are receiving palliative care. They must be aware of the type of support available to them and strategies to help them cope with stress.

6A Follow organisational policies and procedures when managing emotional responses and ethical issues

All organisations have their own guidelines, policies and procedures that are based on legislation and industry standards. The policies of your organisation guide you as to what to do when making a decision or performing a task. The procedures are the step-by-step instructions for completing the task.

Policies and procedures must be made available to you. In some organisations, they are available on the organisation's intranet or in a hard-copy manual in the office or library.



You should be shown where the policy and procedures manual is located when you first start work. Your supervisor will also discuss your duties and obligations as outlined in your job description. It is your responsibility as a healthcare worker to be familiar with, and follow, these procedures. You have a duty of care to the people accessing services and co-workers to ensure that you uphold legislation and industry standards in the workplace at all times.

Included in palliative care policies and procedures is information about end-of-life issues, such as emotional support and related ethical dilemmas.

Understand your own beliefs

It is important that you understand the palliative approach to care, the philosophy behind it and your own feelings and beliefs.

Everyone has different values, ideas and thoughts regarding death and dying. These are formed by a person's background, upbringing, education and culture. However, when you work in palliative care, you must understand and follow the policies and procedures of the organisation you work for. These may be in conflict with your own beliefs and attitudes. If this is the case, you should discuss this with your supervisor.

Working in this area can be very rewarding and satisfying. However, discussing end-of-life issues with people suffering a life-limiting illness is not easy. Taking the person's, their family's and carers' emotional concerns into account and responding empathically can be very stressful and frustrating at times. You should acknowledge your own need for support and self-care as a palliative care professional.

Death and dying reactions

It is important to understand your own emotions about death and dying. The first thing to realise is that everyone is different. Some people remain cool and detached. Others may feel as emotional as the person's family members and carers. A person's culture and background may also affect the way they perceive death and dying.



6B Identify and reflect on your own emotional responses to death and dying

Palliative care means dealing with suffering, pain, distress, anger and grief. People accessing the service may suffer pain. People accessing the service will die. Family members and friends may be demanding or take their grief out on the worker. Dealing with ethical issues, such as ending a person's life by taking them off a life-support system or not providing further treatment, is very emotional. You must be adequately trained to cope with death and bereavement as palliative care is challenging.



Palliative care workers must maintain a steady, professional manner and display understanding, warmth and empathy towards others. They should also maintain their own health and fitness. There is often little time to grieve or talk about feelings with others. This may result in high stress levels for workers.

Recognise and deal with the potential impact of your personal responses on others

Different people will respond differently to a person's death. However, the way a palliative care worker responds to death and dying has an impact on others such as their co-workers, family members, carers and other people who access the service. The worker should provide a calming, supportive environment, which is not possible if they are crying and unable to cope. They may have experienced a loss of their own and be grieving or a death may be one of many recent deaths they have had to deal with. They may have formed a close bond with a person accessing the service in their final days. All these things may cause an emotional response in a worker.

You may experience a range of emotions such as sadness, confusion, fear and anger. Below are ways your reactions can have an impact.

How your reactions may affect your work and others

- ▶ Your work becomes affected by your feelings when you can't perform effectively anymore and are unable to provide the support necessary to family members and friends.
- ▶ If you withdraw as a result of emotions, people accessing the service in the future will be deprived of your high-quality care and effective support.
- ▶ You may develop a fear of death and dying.
- ▶ You may become frustrated and depressed as a result of the powerlessness of a person's situation and your inability to help.
- ▶ You may be personally affected and grieve as if the person accessing the service was your own family member.

Staff support

Staff support groups are another option for teams who have the time to meet. These groups generally work best when led by someone external to the team, who can provide the safety of structure and boundaries.

A coordinator can also provide support to staff by arranging debriefings to review and discuss an especially distressing incident or series of incidents. Discussion about how the incident was handled, how care could have been improved and how staff members were left feeling, promotes a supportive team culture in which emotions can be openly discussed.

Formal appraisals

Formal appraisals by managers are valuable opportunities to identify sources of stress, provide feedback and consider remedial action. Managers can use this opportunity to acknowledge and praise an individual's work while assisting to develop their range of skills through initiatives such as training, taking on different clinical roles, teaching, research and management.

Continuing professional development not only enables support workers to stay current with skills and academic knowledge, but also provides support for their emotional wellbeing.

Relaxation

It is important for staff to be aware of their stress levels. Suffering from stress can cause people to burn out, where they become emotionally exhausted, develop low morale, become withdrawn, unable to cope and have reduced job satisfaction. Learning to relax can release stored muscle tension and bring wide-ranging health benefits. Common relaxation techniques include massage, meditation, yoga and exercise.

Example

Debrief with supervisor

Amanda has been working in palliative care for 18 months. Recently Amanda has been caring for Lucy. Lucy is 6 years old and has been in a coma for 10 months following massive brain damage after a motor vehicle accident. Amanda has a daughter Lucy's age and finds it emotionally very stressful to care for Lucy. Amanda is having difficulty sleeping and is unable to stop thinking about Lucy on her days off. Amanda approaches the supervisor and discusses her anxiety and concerns. The supervisor is able to refer Amanda to a specialist counsellor and arrange a change in work duties to support Amanda.

