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Your role in care planning

Your principal role in contributing to a person's holistic care plan is to help the person assess their physical, emotional and spiritual needs; to support and encourage the care provided by primary and specialist healthcare services; and to contribute to comprehensive and practical suggestions for care.

To work well together in a holistic environment, each person must understand the role and responsibilities of all team members, communicate effectively, cooperate and collaborate well, attend regular meetings and plan their time efficiently.

Your duties and responsibilities

- 1 Initial assessment**
 Contributing to the person's care plan by assessing them, interviewing their family members, making amendments to the care plan when necessary and ensuring the plan is current and accurate
- 2 Referrals**
 Liaising with health professionals and the palliative care team and assisting with referrals
- 3 Communicating with family**
 Speaking with family members to keep them informed of the person's progress, or to seek further information
- 4 Information**
 Providing a range of information to the person, family members and carers
- 5 Emotional support**
 Providing emotional support and counselling family members and carers
- 6 Pain relief**
 Recognising the signs and symptoms of pain and providing pain relief
- 7 Cultural support**
 Providing cultural support, such as interpreters
- 8 Alleviating distress**
 Evaluating and alleviating a person's physical and psychological distress
- 9 Respect**
 Respecting the person's cultural, spiritual and social beliefs and values
- 10 Volunteers**
 Coordinating and training volunteers
- 11 Policy and procedures**
 Following organisational policies and procedures
- 12 Palliative care approach**
 Applying the principles and values of a palliative care approach in day-to-day tasks

However, it is generally not an either/or case of curative versus palliative care; rather, it is a transition from a curative to a palliative approach, to promote the best possible care. It is often the person's wish to stop a curative approach when there is no hope of recovery, so they can be made comfortable in the final stages of their life.

When the decision has been made to transition to a palliative care model treatment, medical interventions are still accessed to ensure comfort and alleviate suffering.

Life-limiting illnesses

Life-limiting illnesses are progressive and it is expected that death will be a direct consequence. This includes malignant and non-malignant illnesses and illnesses that were once referred to as 'terminal' or 'incurable'. You should understand the differences between the following types of life-limiting illnesses, as you may have to discuss them with your co-workers.

Malignant illness

A malignant illness usually becomes progressively worse and may cause death; for example, a cancerous tumour. Cancerous tumours comprise malignant cells and have certain characteristics. They:

- ▶ are invasive
- ▶ usually grow rapidly
- ▶ may recur after removal
- ▶ cause death if growth is not controlled and stopped.

Terminal illness

A terminal illness is one expected to result in the person's death. Terminal (end-of-life) care is a form of palliative care appropriate when the person is in their final weeks or days of life. End-of-life care requires that the person's care decisions are reviewed more frequently; that the care goals are more sharply focused on the person's physical, emotional and spiritual comfort needs; and that adequate support is provided for family members and carers.

Incurable illness

An incurable illness is not likely to be changed or corrected using medical intervention. The illness is beyond the power of skill or medical treatments and medications to remedy it.

Some examples of incurable illnesses are:

- ▶ Ebola
- ▶ lupus erythematosus (lupus)
- ▶ Creutzfeldt-Jakob disease

Irreversible illness

An irreversible illness is one where a person's usual health cannot be regained and is of such severity that recovery is impossible; for example, motor neurone disease.

People with life-limiting illnesses may have their functional capacity, quality of life, communication abilities and psychosocial wellbeing severely compromised. The palliative care team can make significant contributions to the care of these people through appropriate, evidence-based assessments and interventions.

Feelings of guilt and remorse may stem from a bereaved person thinking about what they should have done or said while the deceased person was still alive. The bereaved individual may also feel that they are somehow to blame for the deceased person's death. Guilt and remorse are common reactions to the loss of someone close and should decrease over time.

Anxiety and confusion

Anxiety is a common feeling among people who are grieving, especially if they were very dependent on a person who has died or who is facing death. They may feel anxious about their ability to survive on their own, both emotionally and practically.

An individual may also experience anxiety about the next stages of life before death.

In the early stages of intense grief, an individual may experience confusion, difficulty concentrating and forgetfulness. They may have difficulty carrying out basic tasks and be easily overwhelmed. This usually gradually fades with time.

Change in world view

Losing someone close or a facing death can often bring about a change in the way an individual thinks about the world. This is particularly true of people who lose someone in sudden or traumatic circumstances. A person experiencing a change of world view may:

- ▶ lose or take up a religious faith
- ▶ see the world as a less benign or safe place
- ▶ change the way they think about death
- ▶ become more determined to make a difference in life; for example, they may begin to do volunteer work.

Chronic sorrow

Chronic or ongoing sorrow is often an expression of complex or unresolved grief. Instead of experiencing a range of emotions, including happy memories of the person who has died or of their life, the grieving person cannot move past their deep feelings of loss.

Depression and despair

It is natural to experience feelings of sadness and depression over the loss of someone close or when facing death; however, it is important to understand that grief and what is known as clinical depression are two separate conditions.

Clinical depression involves ongoing feelings of sadness and emptiness that do not go away over time. People experiencing grief have fluctuating emotions, including sadness, but the deep sadness associated with loss lessens over time as the person integrates the loss into their life.

A person who has depression prior to a significant loss may experience a complex grief reaction as they try to deal with both their depression and their grief.

The feeling of despair stems from a sense of hopelessness, futility and lack of comprehension about what has happened or is going to happen. It is a common reaction in the early stages of normal grief as an individual struggles to come to terms with their loss, but if it persists, it can also be an indicator of a complex grief reaction.

Example

Identify care requirements based on the condition or illness of the person

Client name: Hamish Briggs

Date of birth: 11/08/1928

Gender: Male

Diagnosis: Epilepsy and dementia

Personal details

Hamish is Scottish. He is 87 years old and an atheist. He likes listening to blues and jazz music. He also enjoys reading, the outdoors and dancing.

Environment

Hamish has his own room in a residential aged care facility. The family has asked for a cassette recorder so he can play his favourite music. They have also requested a wheelchair because Hamish is almost bedridden. Hamish has a rug knitted by his wife that sits at the side of his bed. He uses this to put over the top of his legs when sitting outside during the day to read a book.

Person's condition

Hamish is withdrawn and has some mental confusion. He shows signs of depression (low mood) and may display disruptive behaviour. He often suffers from a lack of sleep and is sometimes fatigued by the medication he takes to control his epilepsy. The treatment of Hamish's dysphagia is impacted by mild cognitive decline, which results in a loss of appetite. He also has bowel and bladder incontinence.

How to meet the person's physical needs

Hamish is assessed regularly for any pain and discomfort and the appropriate intervention is taken. The appropriate amount of the prescribed medication is provided to manage depression, confusion, insomnia, pain and epilepsy. Medication is also provided for side effects such as vomiting, nausea and diarrhoea. A formulated care plan is available if Hamish has a major seizure. Alternative therapies are also used, such as massaging neck, shoulders and hands with essential oils and listening to music. An appropriate amount of liquid nutrition and hydration is provided four times a day. Rest time has been allocated during the day.

How to meet the person's psychological, social, cultural needs

Contact social worker to organise social contact and volunteers to visit and engage Hamish in social activities such as a book club, bingo, music nights and chat sessions with other people.

End-of-life plans

Circumstances and opinions may change, especially when death seems imminent, so the palliative care team may arrange a conference with the doctor and the family to make sure the goals of care are agreed on, and to check that the person's preferences remain current. Consider the following seven strategies when meeting with the person, their family and carers to discuss the process for making end-of-life ethical decisions.

Ways to help a person and their family make end-of-life ethical decisions

1

Suggest involving others

Suggest to the person that they involve family members, carers or others close to them, so as to minimise the decision-making burden.

2

Encourage the person to make directives

Some individuals may not have an eligible substitute decision-maker or person responsible, or may prefer that no-one makes medical decisions on their behalf. Encourage the person to consider making a more detailed directive in these circumstances, if appropriate.

3

Choose care team members carefully

The care team member/s selected to conduct discussions about end-of-life care with a person should be those who are identified as significantly involved in the active care of the person.

4

Be aware of opportunities for end-of-life discussions

Opportunities for you to begin end-of-life discussions may arise when the person and/or their family or carers inquire about palliative care; when a person says they want to forego recommended life-sustaining treatment; or when they express a wish to die.

5

Consider timing and environment

Advance care planning is most easily accomplished during stable health or after a person has adjusted to a new illness. Utilise a non-threatening environment such as the person's room or a quiet meeting room

6

Ensure the person understands advance care planning

Find out how familiar the person is with advance care planning and explain the goals. For example, plan for the potential loss of their capacity to make decisions, either temporarily or permanently, to ensure they are protected from either unwanted treatment or under treatment.

7

Explain the details

The person usually needs information from you to understand the meaning of the types of therapeutic and comfort scenarios that may arise in their situation, and the benefits and burdens of various treatment options. Key medical terms should be explained in plain English. Allow time for reflection and discussion after this information has been provided.

Practice task 5

1. Identify two areas the palliative care team assess on a regular basis to ensure the best quality of life for a person.

2. Explain holistic care planning for the palliative care.

3. Explain the concept of death for the following developmental stages: infancy, preschool childhood, older childhood, adolescence.

Click to complete Practice task 5

Summary

1. Curative care treats non-malignant illnesses and promotes recovery, while a palliative approach provides relief and comfort to people with life-limiting illnesses.
2. Palliative care takes place in a range of settings and is provided by a team of people with varied and specialised skills and knowledge.
3. A person's individualised care plan documents the holistic care and support to be provided to them. Holistic care ensures all aspects of the persons needs are considered.
4. Palliative care principles and values emphasise quality end-of-life care, ethical behaviour and respect for the person, their family and carers.
5. The beliefs, values and aims of a palliative approach are enshrined in palliative care standards.
6. Specialist palliative care staff are able to manage a person's individual issues in line with palliative care standards.
7. Palliative care is a dynamic model of care that adapts to the changing needs of the person and their family and/or carer.



Topic 2

In this topic you will learn how to:

- 2A** Consult to identify and share information regarding current and changing needs and preferences
- 2B** Respect the person's lifestyle, social, cultural and spiritual choices and needs in developing the care plan
- 2C** Ensure the planning process supports discussion of spiritual and cultural issues in an open and non-judgemental way
- 2D** Demonstrate respect for the roles of the person and carer in planning and decision-making
- 2E** Refer issues outside scope of own role to appropriate member of the care team
- 2F** Communicate to show empathy and provide emotional support

Support individuals to identify their preferences for quality of life choices

Palliative care aims to achieve the best quality of life possible for a person with a life-limiting illness or in the final stages of their life. Encouraging a person's independence is an important part of this philosophy. To do this successfully you should consult with people, give them access to information and let them choose the type of care they want. Respecting a person's values, goals, beliefs and decisions is crucial.

2B Respect the person's lifestyle, social, cultural and spiritual choices and needs in developing the care plan

Everyone has a right to the best quality of care. This includes having their needs, likes, dislikes and preferences regarding their lifestyle, social activities and spiritual needs taken into account when planning their treatment. These aspects will be discussed during the person's initial assessment, outlined in their care plan and regularly reviewed to ensure currency. All members of the healthcare team must follow these directives and respect the person's preferences.



Lifestyle and social needs

A person with a life-limiting illness will be affected by the symptoms of their condition and any medication they are taking; common experiences are nausea, pain and fatigue. They may also be affected by a lack of activity – if they are no longer able to perform activities of daily living their lifestyle may have changed considerably.

People have the right to maintain their quality life for as long as possible, so the way a person wants to live must be respected and their preferences considered when delivering care. A palliative approach takes into account the social needs of the person, such as the need for social support, personal supports and relationships. A lack of social support may lead to deteriorating psychological wellbeing, depression and diminished functional health. The team must therefore make a thorough assessment of the person's social network, including the person's perception, appraisal and interpretation of the contact that is most important to them. Appropriate interventions can then be undertaken to maintain or improve a person's situation.

The care plan should detail the person's lifestyle, their closest family members, friends and the social network they have established. It should also describe the most appropriate way of communicating with the person and their family.

Personal relationships

A palliative approach takes into account the type of personal supports needed and how the person's relationships can be maintained. Be familiar with the person's family, the relationships within the family unit and the support network the person currently has. Identifying the social relationships and functioning of a person's family enables you and other members of the palliative care team to provide appropriate family care. Each family unit may have a different make-up and dynamic. You should first identify the type of family unit.

Communicating with a person's family about their relationships may help you identify a key family member through whom communication with the broader family is best achieved. This may depend on the person's culture. For example, within some

Culture-related choices

At their initial assessment, people may make choices for their care and treatment based on their cultural beliefs. These should be recorded and integrated in the person's care plan and made known to all members of the palliative care team. The more you understand other cultures, the more you appreciate the reasons for providing care in a certain way.

By following the person's cultural care instructions, you ensure the person's needs are met and that they wear the clothing they want, eat the appropriate food and speak in their own language. The following examples illustrate how a person's culture may influence their choices and care.

Clothing

A person may need to wear:

- ▶ a headscarf to cover parts of their face
- ▶ black, if a family member has died
- ▶ a yarmulke (a skullcap worn by Jewish men).

Food and drink

- ▶ Hindus must not eat beef.
- ▶ Muslims fast during daylight hours during the month of Ramadan.
- ▶ Some religions forbid alcohol consumption.

Language

If a person wants to speak in their first language and asks for the services of an interpreter, the interpreter may need to be a certain gender or age.

Body language

In some cultures it is disrespectful to look a person in the eye; in other cultures, the opposite is true and it is polite to maintain eye contact while holding a conversation. In some cultures, people must not stand too close to another person.

Rituals

The person may ask to:

- ▶ read religious texts
- ▶ meditate
- ▶ pray at specific times
- ▶ receive a blessing
- ▶ celebrate a religious or cultural festival.

Personal grooming

Many Muslim women must only receive personal care assistance from female workers.

Recognise behaviours

People accessing palliative care services may be anxious, overwhelmed, at risk of losing control or may have lost control over their own emotions and behaviour. They may be affected by feelings of mistrust, shame, anger, grief or avoidance.

The way you respond to distressed people can either reduce or increase the likelihood of aggressive or violent behaviour. Be observant of cues about a person's emotional state.

Here are some examples of emotional indicators or cues you may observe in people.

Verbal

- ▶ Abusive language
- ▶ Direct threats
- ▶ Fast, non-stop talking
- ▶ Shouting/yelling

Behavioural

- ▶ Grinding teeth
- ▶ Fists clenched, or clenching and unclenching
- ▶ An inability to sit still
- ▶ Uncontrolled gesturing
- ▶ Flaring nostrils

Intuitive

- ▶ Your own sense that there is something wrong
- ▶ Your own feeling of suspicion
- ▶ Your own fear or apprehensiveness

Causes of distress

A person can become distressed if their needs are not being met, if they are forced to do something they do not wish to do or if they feel they are unable to control events in their life. For example, a person's welfare payments may have been stopped because they have not complied with the conditions of payment. This may lead to a situation where the person is unable to pay their rent and risks becoming homeless, understandably a distressing experience.

People who are distressed may feel misunderstood or wronged. It is not unusual for them to want to:

- ▶ be taken seriously
- ▶ have the situation rectified
- ▶ have something done so that the situation does not arise again



Legal considerations

Legislation, regulations and guidelines ensure people receiving palliative care have their rights upheld in terms of receiving quality care, choosing their own treatment, privacy and confidentiality, being able to complain and refusing treatment. It is part of your role and responsibilities to ensure people understand these rights.

In many states, specific legislation is in place that protects both the person's right to refuse treatment and the health worker's duty of care to provide treatment. Each state and territory also has legislation and guidelines regarding advance care directives, which vary from state to state.

Most directives are only effective for people in the terminal stages of an illness or in a persistent vegetative state, who are not competent to make treatment decisions, and if the presenting condition is the one specified on the advance care document.

Substitute decision-makers

When people can no longer make decisions for themselves, a substitute decision-maker is used. The substitute decision-maker must have been nominated by the person as the individual responsible for making decisions about future medical treatment. You must understand the ethical and legal dimensions of this role, specifically that substitute decision-making only comes into effect when a person loses the capacity to make decisions or is unable to understand the nature and complexity of the treatment, and is therefore no longer considered legally capable of making their own decisions regarding medical treatment.



If a family member has been granted a legal right to make decisions on behalf of a person, then an enduring power of attorney (medical treatment) must be sighted by a member of the palliative care team, and its powers and limitations noted in the person's record. If the person's wishes regarding treatment are known and the document stating this has been signed, then these take priority over the wishes of any family members. Any disagreement about the person's prior wishes is usually resolved by further discussion and support by social workers, pastoral care workers or others.

Ethical considerations

Ethics are the values, principles and standards that guide our view of what is good or bad, right or wrong. The ethics of care in a palliative environment mean that you must respect the person's wishes, maintain confidentiality of information, provide quality care and follow instructions that have been recorded in the person's care plan.

Behaving ethically requires a delicate balance between the standard practice of providing quality palliative care and the wishes of each person. For example, while a person may request assistance to end their life, this is illegal in Australia. It is often a matter of balancing preference with reality.

End-of-life decisions

Depending on a person's circumstances, you may be required to discuss and take action on the considerations described below.

Making a will

- ▶ It may be your job to arrange the material, or relevant expert, to help a person prepare their will or update their current will. Ensure you understand any legal considerations when doing this.

Deciding the type of funeral wanted

- ▶ Many people provide instructions about the type of coffin they want and how they want their funeral to be conducted. They may like to talk to you about this as it may help them to feel they are in control and alleviate their fears. Document their wishes.

Treatment or refusal of treatment

- ▶ The palliative approach is focused entirely on the person's preferences and aimed at enhancing their quality of life. Reaching decisions should ideally involve the person's family members, or suitable people acting as the person's proxy, providing information to the palliative care team about the person's preferences, personal values and history.

Deciding how family affairs are to be looked after

- ▶ In some instances, the person may have complex family matters that need to be resolved; for example, financial decisions or interpersonal or relationship matters. It may be your job to provide emotional support for the person at this time.

Location of death

- ▶ Some people want to return to their home. Others want to go to a hospice where they will receive quality care and cause less distress for their loved ones.

Currency of end-of-life plan

A person's plans and preferences regarding their end of life should be regularly discussed and reviewed for currency with the person, family members, guardian, carers, doctor and other palliative care team members, and all decisions documented and signed. Allow people every possible opportunity to contribute to the care planning and decision-making process.

Sometimes, a person living at home may have no end-of-life plan. If they require urgent treatment, decisions may be made quickly without thinking through the consequences. Here are a number of questions you need to consider in these situations so as to make ethical decisions.

Misconceptions about the use of opioids

There are many misconceptions regarding the use of opioids. Here are some details of such misconceptions, along with the facts to correct them

There are time limits for usage

- ▶ Misconception: there is a limit to the length of time a person can use morphine.
- ▶ Fact: the physical and emotional experience of pain is different for everyone; therefore, the use and dose of morphine required varies from person to person. In palliative care, morphine is usually begun at a low dose and continued until the pain is relieved with minimal side effects. There is no limit to how long a person can use morphine, but additional medication may be required depending on the type of pain.

Use it now, and it's ineffective later

- ▶ Misconception: if the person uses an opioid now, it'll be ineffective when they really need it.
- ▶ Fact: this is not true; opioids are very effective pain-relieving drugs that can safely be taken for a long period of time. If a person's pain is severe enough to use opioids, the drug should be used.

The person will become an addict

- ▶ Misconception: the person will become addicted.
- ▶ Fact: addiction is not an issue when opioids are correctly prescribed and used under the supervision of qualified health care workers, to relieve pain. Drug addiction is associated with people who misuse drugs.

Use of opioids means death is imminent

- ▶ Misconception: morphine is only used when death is imminent.
- ▶ Fact: morphine may be used when people experience moderate to severe pain at any time, not just when they are dying. People may require morphine for their pain relief many months before they begin to deteriorate or are close to death, and not everyone who is dying requires morphine.

Example

Provide appropriate information about the use of pain-relieving medication and treatments in consultation

Katie is in the final stages of her life. She has returned home and is being looked after by her family. Family members have been actively involved in all aspects of Katie's care and understand the approach being taken by the palliative care team.

Katie's granddaughter Molly is a registered nurse and acts as the communication link between the palliative care team and the family. Molly participates in care plan discussions about her grandmother and informs the family of changes to Katie's care.



Strategies to maintain dignity

Enhancing the person's dignity must be maintained both during end-of-life care and immediately following death. Specific strategies and considerations are shown below for each of these stages in the person's care.

End-of-life care

When death is imminent, the person's comfort, dignity and quality of care are very important. Practical comfort measures to manage end-of-life symptoms are often more effective than other interventions. To maintain a person's dignity, consider the following:

- ▶ What is the most appropriate clothing for the person: day clothes or bed attire?
- ▶ Would the person prefer to remain in their bed or be transferred to a chair?
- ▶ Would it help the person if they are massaged with lightly scented oil to remove hospital smells?
- ▶ Should the number of visitors be limited to only those the person wants to see?
- ▶ Should mirrors be removed from the room?

Following death

Each state and territory has legal requirements to follow when the death of a person occurs, including notification and certification of death. You need to understand what the requirements are of the organisation you work for. Each task must be done sensitively and with respect for the person so their dignity is retained even after death.

After-death procedures may include:

- ▶ removing any equipment from the body, such as tubes
- ▶ closing the person's eyes and placing their arms by their side
- ▶ maintaining the person's usual facial features; for example, replacing dentures
- ▶ gently washing the body
- ▶ providing the person's family and the palliative care team with a chance to say their farewells before the person's body is removed
- ▶ provide a formal debriefing for the palliative care team.

Example

Maintain the dignity of the person immediately following death

When preparing directives for end of life care, Miriam had explained that she and her family would like to be able to observe some of the rituals of their Jewish faith.

As her condition deteriorated, care staff were expecting family members and friends to gather, and they accommodated this. A rabbi was called to offer comfort and to pray for Miriam.

After death her eyes were closed and her body was covered. Candles were lit and members of the family were allowed to stay with the body until a funeral home collected it. In Jewish law, being around a dead body is considered to cause uncleanness. The washing of the body and preparations for burial were carried out by a special group of volunteers from the Jewish community.



Communicating information

Your responsibility as a palliative care supervisor or coordinator is to understand any changes in a person's preferences and to make sure you inform everyone involved.

You can do this by:

- ▶ updating the person's care plan weekly
- ▶ confirming the situation at team briefing sessions
- ▶ reading the progress notes from the previous shift to keep up to date with the person's wishes.

If there are new or inexperienced staff in your team, make sure they are aware of the need to constantly monitor and review a person's preferences according to the organisation's policy and procedures.

Example

Ensure decisions are reviewed regularly, communicated and recorded

Here is an example of effectively recorded care notes.

Care notes

Person name: Marjory Bicknell

Date of birth: 3 July 1938

Date: 3 January 2017

Time: 10.30 am

Observations:

Marjory was conscious and able to talk and listen. She showed signs of mental anguish and frustration today. Her care plan says she is to be admitted to a nursing home as her condition has deteriorated; she is in the end-of-life stage now. Spoke with her and she now says she wants to stay home. She told me:

'This is where I want to spend my last days. I want to die where I have lived for the last 50 years with my husband and children. I miss my husband terribly and I want to feel close to him. My husband died in our house seven years ago. This is where I belong.'

Action:

Reassured Marjory that it is her decision and arrangements can be made to continue care in her home. Notified Aline (care team leader).

Worker name: Bradley Loak

Signature: *Brad Loak*

Describe what to expect when a person is dying

Family members look to you and other members of the palliative care team to help them understand what to expect when a loved one is dying. In the final days and hours before death, a person may display a number of signs and symptoms that often occur in a predictable pattern. Changes in daily habits, bodily functions and a decline in functional status are observable and often distressing to the person and their family. Anticipating these changes and symptoms, which are described below, and preparing the person and their family members for what to expect may decrease the uncertainty they have at this time.

Social withdrawal

It is usual for a person nearing the end of their life to withdraw and become less concerned about their surroundings. They may begin by losing interest in the newspaper or television, then visitors, and finally in family members and the people most loved. With this withdrawal comes less of a need to communicate with others, even with close family members and carers.

Food

The person may have a decreased need for food and drink, including their favourite foods. This gradual decrease in interest in eating and appetite is one of the hardest things for some family members and carers to accept. You should explain that the person is not starving to death; rather that this reflects the underlying life-limiting illness and their body preparing to die. At this time liquids are preferred to solids and you should follow the person's lead as to what they can ingest.

Sleep

The person may spend more and more time sleeping, even finding it difficult to keep their eyes open. This is due to the impact of their life-limiting illness on the body's metabolism. Allow family members and carers to spend more time with the person when they are most alert.

Disorientation

The person may become confused about time, place and the identity of people around them. They may also experience hallucinations, seeing people who are not there, including seeing family members who have already died. While the person themselves may not be distressed, this can be distressing to others. You may gently orient the person if they ask where they are or what is happening, but there is no need to correct the person if they are not distressed.

Restlessness

The person may become restless and pull at the bed linen. These symptoms are also due to a change in their body's metabolism. Talk calmly with the person so as not to startle them. If the person is a danger to themselves or others, refer the matter to a doctor who can prescribe medication to sedate the person.

Decreased senses

Clarity of hearing and vision may decrease. Use soft lighting in the room and never assume that the person can't hear you, as hearing is often the last of the five senses to be lost.

Support carers of other people

Carers of other individuals may also be affected by a person's death. If they are professional carers they should be able to explain what has happened to the person they are supporting and maintain a calm and professional atmosphere.

If the carer is a family member who has not experienced death before, they may find it difficult to deal with their emotions. In this case, explain to the carer what will happen to the deceased person's body. This may also be an opportunity to give them information about bereavement, how people react and support services that are available so they can be prepared when their own family member dies.



Self-awareness

It is also important to be aware of your own feelings so you can function professionally as part of the team. You may also be upset about a person or not sure how to approach a situation. You may be particularly busy and have not had time to relax or calm down. Make sure you follow the advice you give team members, remain conscious of your own physical condition and find ways to support yourself.

Example

Prepare the person, family, other staff and self for any distressing end-of-life events

Bruce has worked in a residential aged care facility in a small rural community for 10 years. Dianne had been a resident for seven years, before she died recently at age 102. Bruce was very close to Dianne, particularly because she reminded him of his mother, who died without him being able to say goodbye. Following Dianne's death, Bruce grieved openly for her. He cried a lot, kept apart from other staff members and had difficulty concentrating on his work. The care manager, Lorna, suggested that Bruce seek help from the facility's social worker and offered to make an appointment for him.



Practice task 29

1. List two signs that a person is nearing end-of-life.

Meningitis

Meningitis is when the membrane covering the brain and spinal cord becomes inflamed either due to a viral infection or a bacterial infection.

Signs and Symptoms

- ▶ Fever
- ▶ Vomiting
- ▶ Seizures (fits)
- ▶ Headache
- ▶ Irritability and high pitched cry (especially in babies)
- ▶ The soft spot on the top of a baby's head, called the fontanelle, may bulge and look very full
- ▶ Tiredness or drowsiness (lethargy) or hard to wake
- ▶ Stiff neck in older children
- ▶ Dislike of bright lights (photophobia)
- ▶ Rash which may vary in appearance but may look like red/purplish spots which do not turn white when you push on them (nonblanching)
- ▶ Babies may hold their head back or arch their back

Most people recover from meningitis, although it may take a long time if appropriate care and treatment is given.

Encephalitis

Encephalitis is an inflammation of the brain.

Signs and symptoms:

- | | |
|--------------------------|-----------------------------------|
| ▶ Fever | ▶ Disorientation |
| ▶ Headache | ▶ Personality changes |
| ▶ Poor appetite | ▶ Convulsions (seizures) |
| ▶ Loss of energy | ▶ Problems with speech or hearing |
| ▶ A general sick feeling | ▶ Hallucinations |
| ▶ Severe headache | ▶ Memory loss |
| ▶ Nausea and vomiting | ▶ Drowsiness |
| ▶ Stiff neck | ▶ Coma |
| ▶ Confusion | |

In infants, signs to check for are:

- ▶ vomiting
- ▶ a full or bulging soft spot (fontanelle)
- ▶ crying that doesn't stop or that seems worse when an infant is picked up or handled
- ▶ body stiffness.

The stages and phases of bereavement follow the process shown here.

The stages and phases of bereavement

Denial – the person finds it difficult to accept what has happened.

Anger – the person is angry that their loved one has died.

Finding a reason – the person searches for a reason for the death.

Depression – the reality of death starts to sink in, causing sadness and depression.

Acceptance and adjustment – the person understands that a loved one has gone and begins to move on with life.

Debrief

Most organisations have a bereavement program that includes formal and informal debriefings for palliative care staff. Formal opportunities may include meetings with the hospital social worker and/or regular palliative care team meetings.

A timely debriefing can assist in stabilising a workplace and ensure that anyone requiring specific bereavement support receives the assistance they need. Organisations may also provide one-on-one support by arranging professional counselling for colleagues.

An informal debriefing is one in which everyone is given the opportunity to talk about the death and express their emotions by talking about how they feel about the person, including time to cry. Everyone is then permitted to reminisce about the person by recalling funny, sad or tender moments and to talk about other difficult or stressful incidents involving people receiving palliative care. Finally, a discussion of the person's funeral and ways to celebrate the person's life may be explored.

Critical stress debriefing

One effective debriefing method is critical incident stress debriefing. This is usually led by trained peers, counsellors or a healthcare professional who is not actively involved in the specific palliative care case. This structure of debriefing provides the healthcare professionals with a safe and supportive environment in which to share their feelings and emotions in relation to a specific palliative care case, and involves the following seven steps.

Critical incident stress debriefing

1. Introduction – the specific situation is described so participants know why they are meeting.
2. Fact phase – the type of death and what happened is described.
3. Thought phase – participants describe the thoughts they had prior to, during and after the death.
4. Reaction phase – participants talk about their reactions and the emotions they felt or still feel.