Mundagada the Creator

This is the story of Mundagada the rainbow serpent our creator
The creator had created us all, the hills, mountains, rivers, trees
animals and us people
The hands represent our people reaching out to help us, which
is also depicted by the circle of dots that are joined to u/shaped
objects that represent people.
The reason they are joined is this is the journey that is made by
our people to help the ill or injured.

Original painting by Howard (Jo) Butler (Jo completed PEPA
for Aboriginal and Torres Strait Islander Health Workers in 2008)

The Aboriginal and Torres Strait Islander Flags have been used with permission.

The Torres Strait Islander Flag

Description and Meaning:
Green represents the land
Blue represents the sea
White represents peace
The Dhari (headdress) represents Torres Strait Island
people and the five pointed star represents the five major
island groups. The star also symbolises navigation to
represent the seafaring culture of the Torres Straits.
www.dreamtime.net.au

The Aboriginal flag

Description and Meaning:
Black represents the Aboriginal people
Yellow circle represents the sun—the constant re-newer
of life.
Red represents the earth and Aboriginal people’s
relationship with the land. Red also represents ochre
which is used by Aboriginal people in ceremonies.
All personnel involved in PEPA wish to acknowledge the Aboriginal and Torres Strait Islander peoples as First Nation peoples of Australia. Aboriginal and Torres Strait Islander peoples have survived and adapted despite a history of past negative policies. We acknowledge and respect Aboriginal and Torres Strait Islander culture and people.

A Working Party comprising the project coordinator, PEPA Managers, Indigenous project officers and the National PEPA team developed this learning guide for participants. Development of all learning materials related to PEPA for Aboriginal and Torres Strait Islander Health Workers has been overseen by a Reference Group of representatives from health, education and policy sectors of the Aboriginal and Torres Strait Islander community.

Reference Group members

Roslyn Lockhart, (Chairperson) Congress of Aboriginal and Torres Strait Islander Nurses (CATSIN)
Dr Deborah Prior, Project Coordinator, Queensland University of Technology (QUT)
Catherine Jacka, Indigenous Health Unit, Queensland Institute of Medical Research
Stephen Christian, Indigenous Health Coordinator, Queensland Health
Janine Englehardt/Mark Saunders, National Aboriginal Community Controlled Health Organisation
Vlad Aleksandric, Deputy CEO Palliative Care Australia.
Andreas Molt, (2008) Palliative Care Australia
Dr Vinesh Oommen, PEPA Senior Project Officer, QUT
Natasha Myers, PEPA National Coordinator, QUT
Professor Patsy Yates, PEPA Project Lead, QUT

Working Party members

Dr Deborah Prior, Project Coordinator, QUT (Chairperson)
Ellen Sheridan PEPA Manager, Victoria
Cherie Waight, VACCHO, Indigenous Education Officer for PEPA Victoria
Janet Taylor, PEPA Manager, South Australia
Peta Jackson, Indigenous Project Officer, South Australia
John Carson, PEPA Manager, Northern Territory
Cindy Paardekooper, Indigenous Education Officer, Northern Territory
Kathy Parr, PEPA Manager, Western Australia
Dr Vinesh Oommen, PEPA Senior Project Officer, QUT
Natasha Myers, PEPA National Coordinator, QUT
Professor Patsy Yates, PEPA Project Lead, QUT

We acknowledge all PEPA managers for their contribution to the success of the program. The Queensland University of Technology is acknowledged with appreciation of the infrastructure support and overall management of PEPA that ensures optimal quality of products and resources. We thank the project staff of the Australian Government Department of Health and Ageing as the funding body of PEPA, for their guidance and support.
Disclaimer

This resource has been developed and reviewed by palliative care specialists, and is based on best evidence at the time of writing. It is not the responsibility of, nor does it necessarily reflect the views of the organisations to which individual team members may be affiliated or that of the funding body, the Australian Government Department of Health and Ageing.

The information in this learning guide is for educational use only and is provided in good faith without any express or implied warranty. All practitioners need to use sound clinical judgement in individual situations.

Any links offered to websites or other information resources are provided for interest and are viewed at the users own risk. Provision of these links does not constitute endorsement or support for the information, products, services, or persons associated with the related sites.

PEPA for Aboriginal and Torres Strait Islander Health Workers is funded by the Australian Government Department of Health and Ageing under the National Palliative Care Program.

© Commonwealth of Australia 2010

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced by any process without prior written permission from the Commonwealth. Requests and enquiries concerning reproduction and rights should be addressed to the Commonwealth Copyright Administration, Attorney-General’s Department, National Circuit, Barton ACT 2600. For telephone enquiries please ring (02) 6141 6666 or made available online at http://www.ag.gov.au/cca

Suggested citation: PEPA Project Team (2010). PEPA for Aboriginal and Torres Strait Islander Health Workers’ Participant’s Learning Guidelines. Queensland University of Technology: Brisbane.
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>4</td>
</tr>
<tr>
<td>Role of the PEPA Manager</td>
<td>5</td>
</tr>
<tr>
<td>Clinical Placements and Observation Visits</td>
<td>5</td>
</tr>
<tr>
<td>PEPA Learning Objectives</td>
<td>6</td>
</tr>
<tr>
<td>Glossary of Terms</td>
<td>7</td>
</tr>
<tr>
<td>Learning Objectives</td>
<td>9</td>
</tr>
<tr>
<td>1. The Meaning of a Palliative Approach</td>
<td>9</td>
</tr>
<tr>
<td>2. Developing Supportive Networks</td>
<td>12</td>
</tr>
<tr>
<td>3. Recognising Common Symptoms and how these are Treated</td>
<td>13</td>
</tr>
<tr>
<td>4. Assessment Processes in Palliative Care</td>
<td>16</td>
</tr>
<tr>
<td>5. Your Role as a Health Worker/Hospital Liaison Officer in Palliative Care</td>
<td>18</td>
</tr>
<tr>
<td>6. Effective Communication</td>
<td>19</td>
</tr>
<tr>
<td>.......................... Suggested communication methods for supporting individuals and families</td>
<td>20</td>
</tr>
<tr>
<td>.......................... Loss, Grief and Bereavement</td>
<td>21</td>
</tr>
<tr>
<td>Resources</td>
<td>26</td>
</tr>
</tbody>
</table>
Welcome to PEPA

The aim of PEPA is to increase your knowledge and skills for helping individuals and families who are dealing with advanced disease or chronic illness.

PEPA offers you a combination of learning experiences that include workshops, clinical placements or observation visits with a palliative care service and a self direct learning guide.

This learning guide is to help you get the most out of your PEPA experience by giving you some learning activities and providing space for writing about what you learn and how you feel about the topics. You may not be able to complete all the activities given in this learning guide and there could be other activities that suit your particular learning needs. You will be able to discuss your learning needs and goals with your PEPA Manager.

Activity 1

What are your personal goals or learning needs for PEPA?

I want to learn about:

__________________________________________________________________

__________________________________________________________________

My personal learning goals are:

1_________________________________________________________________

2_________________________________________________________________

3_________________________________________________________________

4_________________________________________________________________

Please note: You may be expected to complete a brief written or oral report about your PEPA experience, to share with work colleagues and others. Your PEPA manager will discuss this report if is it required.
Role of the PEPA Manager

The PEPA Manager will assist you to get the most out of your PEPA experience and, if possible or practical, will negotiate the program to suit your personal learning needs.

Name and contact details of your PEPA Manager:

- Name
- Title
- Address
- Contact number
- Email

Clinical placements and observation visits

If you undertake a clinical placement or observation visit to a palliative care unit, a clinical facilitator will help you set a plan for your visit and point out learning opportunities and resources that can help to achieve your goals.

You may have previously worked with a facilitator, or acted as a learning facilitator yourself so will have some idea of how the relationship works. However, if this is something new for you, here are a couple of tips:

- Talk with your clinical facilitator as soon a possible so you can discuss what you want to learn, and can agree on things to do while on clinical placement
- Utilise other learning resources in the clinical setting
- Be clear about your personal learning goals
Undertaking PEPA will give you the opportunity to:

1. discuss the meaning of a **palliative approach**
2. develop **supportive networks** with specialist palliative care providers and other relevant services
3. recognise **common symptoms** of advanced disease and chronic illness and how the symptoms are treated
4. contribute to the **assessment process** used in palliative care
5. understand **your role** as a Health Worker in palliative care
6. apply **effective communication** to support individuals and families
7. understand people’s **response to loss, grief and bereavement**

There are several learning activities suggested or used in this guide, examples are listed here:

- Talking with specialists, other colleagues, families, individuals and elders
- Clinical observation & activity
- Writing
- Reading
- Reflection / thinking
Palliative care - short definition

Palliative care is specialist care provided for people of all ages who have advanced or chronic illness with little or no prospect of a cure and for whom the primary goal of care is quality of life.

World Health Organization (WHO) definition of palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

• provides relief from pain and other distressing symptoms;
• affirms life and regards dying as a normal process;
• intends neither to hasten nor postpone death;
• integrates the psychological and spiritual aspects of patient care;
• offers a support system to help the family cope during the patient’s illness and in their own bereavement;
• uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
• will enhance quality of life and may also positively influence the course of illness;
• is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO definition of palliative care for children

Palliative care for children is a special and closely related field to adult palliative care. Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves support for the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child’s physical, psychosocial and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources. It can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities [hospitals], in community health centres and even in children’s homes.

Glossary of terms

Palliative approach
A palliative approach is a term used to describe care that aims to improve the quality of life for individuals and their families dealing with an eventually fatal condition, by reducing their suffering through early identification, assessment and treatment of pain, physical, psychological, social, cultural and spiritual needs.

Palliation
To palliate is to reduce the effects of a symptom without curing the underlying medical condition that is causing the problem. Palliation helps a person feel more comfortable and improves quality of life but does not cure the disease or illness.

End of life care
End of life care combines the broad set of health and community services that care for the person nearing the end of physical life and offers support for their family.

Quality end of life care happens when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists and support care providers and the community – working together to meet the needs of people requiring care.

Primary carer
The primary carer is usually a person in the close kin network of the sick person. The primary carer may be the sick person’s partner or spouse, son or daughter, or other family member or friend. The primary carer may be supported by other carers, but generally take on a primary role in the co-ordination and delivery of care and support for the sick person. The primary carer provides for the practical needs of the sick person and takes on tasks that may be of a technical nature such as administration of medications.

**Objective 1**

**Introduction - the meaning of a palliative approach**

People with advanced disease or chronic illness that causes worrying symptoms can benefit from a palliative approach to their treatment and general health care.

A palliative approach aims to protect individuals and families from unnecessary suffering by treating, relieving and reducing symptoms and supporting the person and family emotionally.

**Explaining a palliative approach to individuals and families**

In Western Australia the Cancer Council, local palliative care specialists and Aboriginal medical service providers developed an explanation of palliative care for the general community, which you may find useful. The WA explanation about palliative care states:

- Palliative care helps people of all ages when they get very sick with an illness that is not expected to get better
- Many health care people are involved in providing palliative care including health professionals, priests and local elders
- The work of palliative health care people is to take away the sick person’s pain and other symptoms and problems, and to help the family look after them
- Palliative care health people will listen carefully to what the person and their family want

**Activity 2**

How would you explain a palliative approach to a sick person and their family in your community?

---

4 Cancer Council of Western Australia, DVD- Providing culturally appropriate palliative care, 2005
Key points about a palliative approach

- A palliative approach can be implemented in any location but it is important that the service is provided where the person and the family want to be.

- The palliative approach can be provided in a person’s home, aged care facility, other areas of the general community, in a hospital or specialist palliative care unit.

- The palliative approach is appropriate at anytime during the person’s sickness when they have worrying symptoms. Some people may just need a short time to control their symptoms while others require a longer period as their illness gets worse.

- A palliative approach extends to offer supportive care for individuals and families during their time of grief and bereavement.

- The distress of the sick person and their family can be made worse if they are not aware of the services and resources available to help and support them.

- Palliative care is an holistic approach that aims to address the physical, emotional, psychological, social, cultural and spiritual worries of the sick person.

- The palliative approach aims to embrace the sick person, their family, friends and community.

- Applying a palliative approach involves a team of health care providers that work with the individual, their primary carer and other members of the family.

- The palliative care specialist team may directly manage the person’s needs or provide advice to the primary health care team in the person’s community. It is important to inform the family about the members of the palliative care team.

Diagram 1 shows the composition of the many health care people who can be part of a palliative care team. This model was adapted from the original to include Aboriginal and Torres Strait Islander Health Workers and cultural brokers.

Adapted from the Palliative Care Council South Australia, www.pallcare.asn.au
Palliative care providers come from diverse faiths, spiritual traditions and racial backgrounds, but in their own way all hold common qualities of compassion, kindness, respect of life and respect for others with different beliefs and values.

It is important that palliative care service providers liaise with their local Aboriginal or Torres Strait Islander Health Workers and the general Indigenous community, for guidance on specific cultural practices and requirements related to end-of life care and spiritual care for Indigenous peoples.
Developing supportive networks

The first step towards developing a supportive network is getting to know the palliative care specialists that serve your local area. The palliative care service may be based in a regional hospital or in the community.

Activity 3

Find out the names and contact details of the palliative care team members in your region. This list can be a useful reference for you and others in your work place.

Your PEPA manager or clinical facilitator can help you fill out this section

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Name</th>
<th>Contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Director Palliative Medicine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Nurse Manager/Consultant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consultant in Palliative Medicine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Registrar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Medical Practitioner (GP)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses – Hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses – Community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal and Torres Strait Islander</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital Liaison Officer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal and Torres Strait Islander</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Worker - Community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteer Coordinator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pastoral Care Worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual Care Worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grief and Bereavement Counsellor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local Pharmacists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteers in Community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteers in Hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advance Care Planning Coordinator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physiotherapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dietician</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Staff</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Recognising common symptoms and how these are treated

Activity 4

Think about a person you know who has an advanced or chronic illness. What symptoms of the illness did this person have?

Which symptoms worried them the most?

What was done to relieve the person’s symptoms?

It is understood that people with advanced disease or chronic illness may have psychosocial and spiritual symptoms that worry them the most however, in this section the focus is mainly about physical symptoms.

Activity 5

During your PEPA workshop and/or clinical placement write down what you learn about patients’ symptoms and how they are treated in palliative care.

Common physical symptoms associated with advanced or chronic illness

Advanced disease and chronic illness give rise to a number of symptoms as the condition worsens. Table 1 lists physical symptoms that are common in advanced disease and chronic illness.
### Activity 6

Table 1.

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>PALLIATIVE TREATMENT/ MANAGEMENT TECHNIQUES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pain</strong></td>
<td></td>
</tr>
<tr>
<td>Gastric problems-</td>
<td></td>
</tr>
<tr>
<td>• vomiting</td>
<td></td>
</tr>
<tr>
<td>• nausea</td>
<td></td>
</tr>
<tr>
<td>• constipation (blocked up)</td>
<td></td>
</tr>
<tr>
<td>• diarrhoea (belly runs)</td>
<td></td>
</tr>
<tr>
<td>Breathing difficulties</td>
<td></td>
</tr>
<tr>
<td>• shortness of breath</td>
<td></td>
</tr>
<tr>
<td>• coughing - dry or moist cough</td>
<td></td>
</tr>
<tr>
<td>Reduced energy levels</td>
<td></td>
</tr>
<tr>
<td>Loss of appetite</td>
<td></td>
</tr>
<tr>
<td>Difficulty swallowing food</td>
<td></td>
</tr>
<tr>
<td>Dry mouth</td>
<td></td>
</tr>
<tr>
<td>Skin problems</td>
<td></td>
</tr>
<tr>
<td>• itching</td>
<td></td>
</tr>
<tr>
<td>• dryness</td>
<td></td>
</tr>
<tr>
<td>Infections</td>
<td></td>
</tr>
<tr>
<td>Insomnia-lack of sleep</td>
<td></td>
</tr>
<tr>
<td>Nightmares</td>
<td></td>
</tr>
<tr>
<td>Other symptoms</td>
<td></td>
</tr>
</tbody>
</table>
Activity 7

Note down other symptoms (not listed in Table 1), that you witness while on your PEPA clinical placement and describe how these were treated.

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Signs and symptoms of the final stage of a person’s illness

There are certain symptoms or changes which indicate that the person’s illness is at the final stage and the person is nearing the end of physical life. It is important to recognise these symptoms so you can help the person’s family and friends by explaining that the symptoms are expected.

Symptoms that indicate a person is near the end-stage of their illness (this will vary according to the person’s condition) may include:

- Peripheral shutdown seen as changed skin colour which may look blotchy
- Loss of appetite, the person refuses any offer of food
- Profound weakness
- Drowsiness, unresponsive to other people
- Irregular and noisy breathing
- Retained upper airway secretions heard as ‘gurgling or bubbling’ noises in the throat
- Difficulty swallowing
- Restlessness, agitation, muscle twitching,
- Pulling at the bed covers
- Longer periods of semi-consciousness with laps of unconsciousness
- Moaning, calling out 5

Activity 8

Talk with your clinical facilitator or another palliative care specialist about how the signs and symptoms of the final stage of an illness are managed.

Use this space to write what you learn about end of life care, and add your personal reflections about the process.

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Assessment processes in palliative care

Assessment is an essential process to ensure that the sick person and their family’s worries and concerns are known and that appropriate intervention or treatment is provided.

All health care providers serving individuals and families, contribute to the assessment process.

It is important to apply an holistic approach which means considering all domains of the person’s life when assessing their symptoms. The five domains of care are shown in diagram 2, which symbolises the circle of palliative care.

Diagram 2. The Five Domains of Holistic Care
Activity 9

Check out the assessment methods and how the observations are recorded in the palliative care service that you visit.

Some guidelines for assessment in palliative care

- Listen to the sick person and their family’s story about the sickness and symptoms
- Look for contributing factors or situations that make the symptoms worse, for example: movement, position, emotions, anxiety, fear
- Ask about the person’s treatment, medications and other therapies they are using
- Ask the person and their family about home remedies, traditional medicines or healing practice that they prefer to use
- Observe the person for signs and symptoms of changes in their physical condition
- Ask the sick person what is worrying them the most
- Talk to the person’s primary carer(s) about changes or symptoms they have noticed
- Check for other changes in the person’s spiritual, emotional, cultural, social and family needs
**Objective 5**

**Your role as a Health Worker/Hospital Liaison officer in palliative care**

Your role in palliative care will vary according to the area or location in which you work. General ways that Health Workers can contribute to the care of individuals and families dealing with advanced or chronic illness are listed below:

- Liaise with palliative care specialists
- Advocate for individual's and family's particular needs
- Facilitate advanced care planning with the individual and their family
- Provide information about palliative care to the community
- Negotiate time and space for families to be with the sick person
- Educate individuals and families about the available services
- Educate palliative care services about cultural issues
- Coordinate practical help for example, transport, home equipment, beds, cooking and meals, domestic help etc.
- Help individuals and families to navigate the system of palliative care services
- Provide supportive care for the sick person and families
- Coordinate respite (time out) for the primary carer and family
- Ensure a good environment for the sick person, whether in hospital or at home
- Help the sick person with their medications

**Activity 9**

Take a moment to think about other ways you can help the sick person and their family.

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
Effective communication

Effective communication is a vital skill for supporting the person and their family. The basic purpose of communication is to share thoughts or information between people and usually involves verbal and non-verbal processes.

When using verbal communication the information must be accurate and precise, because the sick person and their family are depending on what they are told. A golden rule is if you are unsure of something then refer the enquiry to someone who has the information required. Also be aware of your non-verbal communication as it may send the wrong message.

There are three personal qualities of an effective communicator in palliative care:

- **Unconditional positive regard** (Rogers, 1967)⁶ for the person and their family. This means valuing and accepting the person and their family without judgements or biases. The term unconditional refers to the idea that professional health care is offered without preconditions, expectation or demands on the person or their family.

- **Empathy** which is the ability to understand what the person is experiencing and to see the world as they do.

- **Warmth and genuineness** is the ability to convey you care and that you are there for the person and their family. It is more a state of mind than a skill and therefore shows in your attitude and non-verbal communication toward others. Being genuine starts with self-awareness of your personal feelings and attitudes and how these might affect the person and family you are caring for.

Communication methods for supporting individuals and families

- Listen respectfully
- Provide information about symptoms the sick person maybe experiencing
- Show understanding, empathy and sympathy
- Provide information about coping behaviours and how these may show up when people are dealing with bad news relating to their sickness
- Encourage the person and their family/friends to talk about the good times, and to share stories and yarning
- Give time to find out what the individual needs and wants
- Talk about advanced care planning to ensure the individual's and family's wishes are known to the palliative care team
- Encourage relaxation, meditation and other self-care skills you know
- Refer to other workers who have the appropriate skills to provide grief counselling and supportive bereavement care if necessary

Activity 10

Use this space to write down other communication methods or strategies that you learn about from your PEPA workshop and/or clinical placement.

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

PEPA learning objectives

Undertaking PEPA will give you the opportunity to:

1. discuss the meaning of a palliative approach
2. develop supportive networks with specialist palliative care providers and other relevant services
3. recognise common symptoms of advanced disease and chronic illness and how the symptoms are treated
4. contribute to the assessment process used in palliative care
5. understand your role as a Health Worker in palliative care
6. apply effective communication to support individuals and families
7. understand people's response to loss, grief and bereavement

There are several learning methods suggested or used in this guide, examples are listed here.
Loss, grief and bereavement

Loss, grief and bereavement are normal experiences of life. The pain of loss and grief and bereavement can be experienced physically, emotionally, spiritually or culturally and the consequences can affect social and family relationships.

Everyone experiences loss and grief and responds in their own way, even people in the same family may react differently. Research of different life events has identified common behaviour of people dealing with loss, grief and bereavement. Your understanding of people’s response to loss, grief and bereavement equips you to better support individuals and families.

Definitions

Loss is the experience of separation from something or someone to which we are emotionally attached.

Grief is the response or reaction to loss and the period of adjustment to that loss.

Bereavement is the period of grief after a death of a loved one or other significant people in our life.

Activity 11

The sick person who is nearing the end of physical life deals with many losses, take a moment to think about what these loses might be.

Write down the losses the sick person may experience.
The way people cope with loss is influenced by their personal style and how they have dealt with losses before. Some people have had to deal with several quite devastating losses during their life, for example, the loss of a child, or loss of the family home through bush fires or loss of loved ones through accidents or violence.

Grief is an emotional and physical response to loss. There is no one-way to grieve; the experience is as individual as the people themselves.

Any of the following responses can be experienced by people who are grieving:

- **Mental**: confusion, preoccupation, hallucinations, dreams of the deceased person
- **Emotional**: sadness, guilt, anxiety, loneliness, fatigue, longing, hopelessness, relief,
- **Physical**: hollowness in the stomach, tightness in the chest, tightness in the throat, breathlessness, dry mouth, digestive and related problems
- **Behavioural**: over activity, projection of feelings, avoiding reminders of the deceased, or visiting places and carrying reminders or treasured objects of the deceased
- **Spiritual**: Feelings of anger, feeling alienation from God, feeling life has lost its meaning, social isolation, depression.

Other grief reactions

<table>
<thead>
<tr>
<th>Mental</th>
<th>Emotional</th>
<th>Physical</th>
<th>Behavioural</th>
<th>Spiritual</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Disbelief</td>
<td>• Fear</td>
<td>• Over-sensitivity</td>
<td>• Crying</td>
<td>• Questioning the meaning of existence</td>
</tr>
<tr>
<td>• Numbness</td>
<td>• Sadness</td>
<td>• A sense of depersonalisation</td>
<td>• Sighing</td>
<td></td>
</tr>
<tr>
<td>• Denial</td>
<td>• Anger</td>
<td>• Breathlessness</td>
<td>• Sleep disturbances</td>
<td></td>
</tr>
<tr>
<td>• Preoccupation</td>
<td>• Guilt</td>
<td>• Muscle weakness</td>
<td>• Absent-mindedness</td>
<td></td>
</tr>
<tr>
<td>• Sense of the</td>
<td>• Inadequacy</td>
<td>• Lack of energy</td>
<td>• Social withdrawal</td>
<td></td>
</tr>
<tr>
<td>dead person’s</td>
<td>• Hurt</td>
<td>• Loss of appetite</td>
<td>• Restlessness</td>
<td></td>
</tr>
<tr>
<td>presence</td>
<td>• Relief</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Loneliness</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

It is important to note that the grief response processes listed here, are not meant to be a checklist that a person has to get through. Everyone is different; people can experience one or many responses in any order and at any time. You will have an opportunity to discuss the process of grieving during your PEPA workshop.

---

Bereavement is the period of grieving experienced by family and friends after a loved one has passed on. When we lose someone our feelings can be very confusing, we can be angry, sad and guilty all at the same time. It is important to give extra support for people during their bereavement, because they need time to adjust to their loss.

Bereavement care can take the form of a telephone call, a visit from a counsellor, health worker, or volunteer trained for this type of work. Some palliative care organisations have an annual memorial service for the families of people who have passed on.

Extreme grief
Responses to grief and bereavement such as chest pain, digestive upsets, breathlessness, hallucinations, sleep disturbance and extreme sadness, could also be symptoms of other health problems. It is therefore important to advise the person to get checked out by their doctor if these symptoms become troubling to the individual or their family.

The grief reactions and behaviours of some people can be so extreme that it moves beyond what is considered ‘normal’ to a pathological or complicated grief. People displaying behaviours of complicated grief require additional professional intervention and counselling.

The following behaviours are signs of complicated grief.

- Intense intrusive thoughts
- Pangs of severe emotions
- Distressing yearning - excessive longing for the person who has passed on
- Feeling incredibly alone and empty
- Excessively avoiding tasks reminiscent of the deceased person
- Unusual sleep patterns
- Maladaptive levels of loss of interest in personal activities

Extreme grief and suicide

Extreme grief may also manifest as suicidal thoughts and behaviours such as self-harming, talking or writing about death and suicide, rage, anger and seeking revenge. The person at risk of suicide must be referred to the mental health services.

Other signs of extreme grief that require professional help are those relating to increased risk taking behaviours such as, excessive use of alcohol or drugs and self harming behaviour.

If you have access to the internet the Mental Health first aid guidelines may be useful, you can access these either from www.healthinfonet.ecu.edu.au or www.mhfa.com.au

---


9 ibid
Activity 12

During your PEPA workshops and/or clinical placement, check out the services offered to help people who are grieving or who have been bereaved.

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

Health care workers also grieve

It is normal for you in your role as a health care worker to become quite attached to the people you care for. So you can expect to experience some of the symptoms of grief when witnessing a decline in the health of the sick person, especially when they have passed on. In addition you may experience deeper feelings of grief if you know or are related to the grieving families in your community.

It is important for your health that you acknowledge your grief and find time to share feelings with other colleagues, friends or family members.

You may also find it useful to record your thoughts and feeling in your personal journal.
Activity 13

List some ways that you care for yourself.

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

How do you deal with your grief when a person in your professional care has passed on?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

During your PEPA workshop or clinical placement ask about the different ways that carers are supported in their grief. Also find out what type of bereavement care is provided for families in your local area.

Supporting each other when experiencing grief does not have to be a formal event, sometimes just a chat over a coffee/tea can be enough. Attending a person’s funeral as well as showing your respect for the person who has passed on and supporting their family, may also bring you comfort.

Activity 14

Check out the services and resources for individuals and families dealing with loss, grief and bereavement in your local area.

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Congratulations, you have reached the end of the PEPA Learning Guide. You are encouraged to review the learning activities for your ongoing professional development and also to share these with your work colleagues.
A list of resources and details of the national palliative care peak body are provided here to conclude this learning guide. The resources listed here may help you when attending to individuals and families dealing with advanced disease and chronic illness.

Palliative Care Australia (PCA) is the peak national body representing the interests and aspirations of all who share the ideal of quality care at the end of life for all people. PCA has a number of resources and information booklets which may be helpful to you and the people you care for. There are member organisations of PCA in each state and territory, check out the web site [www.pallitivarecare.org.au](http://www.pallitivarecare.org.au) for more information.

### List of Resources

<table>
<thead>
<tr>
<th>Title</th>
<th>Format</th>
<th>Publisher</th>
<th>Available</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Providing Culturally Appropriate Palliative Care to Aboriginal and Torres Strait Islander Peoples - Resource Kit 2004</td>
<td>A4 folder including CD</td>
<td>Prepared for DoHA by Mungabareena Aboriginal Corporation, Wodonga Institute of TAFE and Mercy Health Service Albury</td>
<td>Available free of charge by using the publications order form at <a href="http://www.palliativecare.gov.au">www.palliativecare.gov.au</a></td>
</tr>
<tr>
<td>2. Providing Culturally Appropriate Palliative Care to Aboriginal People in South Australia - Resource Kit 2005</td>
<td>Yellow folder includes: Practice Principles, Companion Guide Pamphlet - Palliative Care: Some questions answered</td>
<td>Supplement to national resource kit by South Australian DoHA</td>
<td>Department of Health PO Box 287 Rundle Mall Adelaide SA 5000 Phone: 08 8226 6482 Fax: 08 8226 6633 Website: <a href="http://www.pallcare.asn.au/aboriginalcaresa">www.pallcare.asn.au/aboriginalcaresa</a></td>
</tr>
<tr>
<td>3. Providing Culturally Appropriate Palliative Care to Aboriginal People in WA 2006</td>
<td>Booklet + CD</td>
<td>Supplement to national resource kit by The Cancer Council WA</td>
<td>Cancer Council WA 46 Ventnor Avenue West Perth WA 6005 Phone: 08 9212 4333 Fax: 08 9212 4334 Website: <a href="http://www.cancerwa.asn.au">www.cancerwa.asn.au</a></td>
</tr>
<tr>
<td>4. Bessie’s story: Palliative Care in Remote Aboriginal Communities 1998, Reprint 2008</td>
<td>Booklet</td>
<td>North West Regional Palliative Care Committee Kimberley Palliative Care Service</td>
<td>Nunzio Pindan Printing, Broome <a href="mailto:pindan@wn.com.au">pindan@wn.com.au</a> Mobile phone: 0418 587 166 or Palliative care Service Broome, WA Ph.(08) 9192 2022 Fax. 9193 6280</td>
</tr>
<tr>
<td>5. Cultural protocols (Aboriginal people) 2006</td>
<td>A4 Chart</td>
<td>Western Adelaide Palliative Care, The Queen Elizabeth Hospital (DoHA funded)</td>
<td>Unspecified</td>
</tr>
<tr>
<td>6. The “Living Model”: A resource manual for Indigenous Palliative Care Service Delivery 2006</td>
<td>Resource Manual</td>
<td>Authors: Pam McGrath and Hamish Holewa Publisher: Researchman PO Box 796 Toowong Qld 4067</td>
<td>Unspecified</td>
</tr>
<tr>
<td>Title</td>
<td>Format</td>
<td>Publisher</td>
<td>Available</td>
</tr>
<tr>
<td>-----------------------------------------------------------</td>
<td>-------------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>7. Relieving Your Grieving: Palliative Care and Illness</td>
<td>A4 Brochure + A5 Pamphlet</td>
<td>ACT Health</td>
<td>ACT Health, Communications and Marketing GPO Box 825 Canberra ACT 2601 Publication No 06/0302</td>
</tr>
<tr>
<td>Counselling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Relieving Your Grieving: Palliative Care and Illness</td>
<td>A4 Brochure</td>
<td>ACT Health</td>
<td>ACT Health, Communications and Marketing GPO Box 825 Canberra ACT 2601</td>
</tr>
<tr>
<td>Counselling – for kids</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Loss and Grief: Helping Aboriginal People Cope –</td>
<td>Booklet</td>
<td>Social Emotional Wellbeing Team at Central Australian Aboriginal Congress</td>
<td>Central Australian Aboriginal Congress, Social Emotional Wellbeing Branch Phone: (08) 8951 4457 Website: <a href="http://www.caac.org.au">www.caac.org.au</a></td>
</tr>
<tr>
<td>where to go for help</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Victorian Indigenous Palliative Care Project 2005</td>
<td>Booklet</td>
<td>Department of Human Services Victoria (funded by DoHA). Contracted with VACCHO.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Islander People.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Caring for Elizabeth</td>
<td>DVD</td>
<td>Kimberly Palliative Care 08 9192 9295 Email: <a href="mailto:kpcs@health.wa.gov.au">kpcs@health.wa.gov.au</a></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Aboriginal and Torres Strait Islander Carers.</td>
<td>Booklet</td>
<td>National Respite for Carers Program, Australian Government</td>
<td>Commonwealth Respite and Carelink Centre 1800 059 059 and 1800 636 242 Website: <a href="http://www.palliativecare.gov.au">www.palliativecare.gov.au</a></td>
</tr>
<tr>
<td>Caring for our People 2008</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Now What? Understanding Grief</td>
<td>Brochure</td>
<td>Palliative Care Australia (PCA)</td>
<td>ph. 02 6232 4433 fax. 02 6232 4434 <a href="http://www.palliativecare.org.au">www.palliativecare.org.au</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Sorry business- Grief and Loss</td>
<td>Brochure</td>
<td>Indigenous substance misuse health promotion, South Australia</td>
<td>ph. 08 8362 0395 fax. 08. 83620327 (Cost approx. 0.75c per leaflet) <a href="http://www.adac.org.au">www.adac.org.au</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Telling your story. Getting over grief</td>
<td>Brochure</td>
<td>Indigenous substance misuse health promotion, South Australia</td>
<td>ph. 08 8362 0395 fax. 08. 83620327 <a href="http://www.adac.org.au">www.adac.org.au</a></td>
</tr>
<tr>
<td>19. When someone dies: What do we tell the children?</td>
<td>Brochure</td>
<td>Indigenous substance misuse health promotion, South Australia</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Understanding Morphine (Creole version also available)</td>
<td>Booklet</td>
<td>The Cancer Council Qld</td>
<td>The Cancer Council Qld</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Going Home</td>
<td>CD</td>
<td>VACCHO Kutcha Edwards</td>
<td>ph.02 6232 4433 fax. 02 6232 4434 <a href="http://www.palliativecare.org.au">www.palliativecare.org.au</a></td>
</tr>
</tbody>
</table>
Other related resources

<table>
<thead>
<tr>
<th>Title</th>
<th>Format</th>
<th>Year</th>
<th>Publisher</th>
<th>Available</th>
</tr>
</thead>
</table>
| 1. Therapeutic Guidelines:  
  Phone: 03 9329 1566  
  Or 1800 061 260  
  Fax: 03 9326 5632  
  Email: sales@tg.com.au  
| 2. Palliative and End of Life Care, Glossary of Terms, Edition 1, 2008 | Booklet                       | 2008       | Palliative Care Australia               | Palliative Care Australia  
  PO Box 24  
  Deakin West ACT 2600  
  Phone: 02 6232 4433  
  Fax: 02 6232 4434  
  Website: [www.palliativecare.org.au](http://www.palliativecare.org.au) |
| 5. Palliative care dementia resource kit                               | Online resource, information for patients and families | 2009       | ACH Group, South Australia              | [www.ach.org.au](http://www.ach.org.au)                                  |