LEARNING GUIDE FOR ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH WORKERS
ACKNOWLEDGEMENT

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- State and Territory PEPA Managers
- State and Territory PEPA Aboriginal Project Officers and consultants
- Projects Officers from the Australian Government Department of Health
- Project Director Professor Patsy Yates, Queensland University of Technology

The palliative approach to care workshop has been developed for Aboriginal and Torres Strait Islander Health Workers, Aboriginal and Torres Strait Islander Health Practitioners, Community Workers and Community members. Throughout this document the term ‘health care providers’ will be used to refer to all of these groups.

This resource has been developed by the PEPA National Indigenous Coordinator, Catherine Jacka and Project Consultant Dr Deborah Prior. The material in this resource draws on previously developed PEPA resources including the Nurses and Allied Health Professionals Learning Guide, the PEPA Mentoring Guide and the PEPA Program for Aboriginal and Torres Strait Islander Health Workers Learning Guide.

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RECOGNITION

The PEPA team acknowledges Aboriginal peoples & Torres Strait Islander peoples as Australia’s First Nation peoples, the Traditional Owners and Custodians of the country known as Australia.

Aboriginal Flag designed by Harold Thomas, an Aboriginal artist, in 1971.

The black represents the Aboriginal people, the red the earth and the spiritual relationship to the land, and the yellow the sun, the giver of life.

Torres Strait Islander Flag attributed to the late Bernard Namok of Thursday Island.

The green stripes represent the land, the black stripes represent the people, and the blue the sea, the white “Dhari” (headdress) is a symbol of Torres Strait Islanders and the white five pointed star symbolises the five major island groups.

The PEPA team acknowledges and is respectful of the sensitive nature of the end of life care journey.

The PEPA team would like to recognise the contributions and partnerships of Aboriginal Australians and non-Aboriginal Australians in the development, promotion and delivery of this experiential learning about the end-of-life care journey. Working together to benefit all health care providers.

This resource for the Program of Experience in the Palliative Approach (PEPA) has been developed with funding from the Australian Government Department of Health. http://www.health.gov.au/palliativecare

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.
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WELCOME TO PEPA

The Program of Experience in the Palliative Approach

The PEPA team recognises palliative care is sensitive business and respects the journey that you are taking to improve the quality of life for those with life limiting illnesses and their families.

The palliative approach reflects a positive and open attitude towards finishing up/death and dying, although this is not confined to the end stages of illness. We will focus on active comfort care and a positive approach to reducing symptoms and distress, while promoting understanding of loss and bereavement with family and community. This approach facilitates early identification of the sick person’s concerns, beliefs, needs and choices to be implemented during the end of life care path.

This Learning Guide is the workbook for the experiential learning pathway with PEPA. It contains:

1. Your welcome and introduction to PEPA
2. The Workshop. Palliative Approach to Care includes a range of individual and group learning activities. ‘Pop Arthur’, an Australian Indigenous comic book, will be used throughout the workshop to provide materials to generate discussion and reflection
3. The Workplace Placement to enable learning experiences to further develop and enhance skills, knowledge and confidence in the palliative approach. Resources for your workplace activity are also included in this guide
4. The Palliative Care Resources section and includes policies, research findings and recommendations, practical resources created used and distributed by Aboriginal health care providers, websites and journals which may be of interest to you.
PEPA PATHWAY

Do you care for people who have a chronic or advanced illness who are unlikely to get better?

The Program of Experience in the Palliative Approach (PEPA) offers funded learning opportunities for health care providers with a pathway to develop and enhance skills, knowledge and confidence in the palliative approach. This experiential pathway provides a range of learning activities that include workshops and workforce placements with a specialist palliative care service. Workshops and workforce placements are available in all Australian states and territories for health care providers including Aboriginal and Torres Strait Islander health workers, health practitioners and community workers, medical practitioners (including GP registrars), community care workers, nurses, migrant and CALD workers, aged care workers and allied health professionals working in primary care or non-specialist palliative care settings. We encourage applications from health care providers working in these roles in regional, rural and remote areas.

The focus of PEPA is on assisting you to expand your knowledge and skills in the palliative approach to care. This opportunity is not designed to develop you as a specialist palliative care provider, but rather to assist you to incorporate the principles of palliative approach to care.
The aims of the palliative approach experiential learning pathway for Aboriginal and Torres Strait Islander health care providers are to:

- Further improve the skill and confidence of health care providers across a variety of health care settings to work with sick people from diverse backgrounds with palliative care needs
- Provide opportunities to ensure health care providers across the continuum become aware of and provide culturally appropriate palliative care including supporting care preferences, bereavement expression, cultural and spiritual requirements
- Establish and enhance linkages between specialist palliative care and other health care providers involved in caring for sick people and families at end of life.

To achieve these aims, PEPA provides a range of learning activities that involve structured learning programs to create an experiential learning pathway in the palliative approach. All activities are available to all health care providers. The learning activities include:
PEPA WORKSHOPS: Your previous experiences will direct you to choose the workshop that meets your need:

**The Palliative Approach to Care Workshop**
Holistic focus with clinical aspects, is available to single or multi-discipline audiences

**Culture and Diversity in Palliative Care Workshops**
Aboriginal and Torres Strait Islander Perspectives OR Culturally and Linguistically Diverse Community Perspectives

**Community Outreach Programs**
Introduction to the palliative approach, delivered in community venues to Aboriginal and Torres Strait Islander health care providers, community professionals and community members. This program is flexible and customised to local needs

**Aged Care Workshops**
Develop knowledge and skills in the palliative approach for the aged care workforce.

**PEPA Workforce Placements entail:**
- 2-5 days in community, inpatient and hospital based consultancy specialist service
- Supervised, observational placement, guided by a mentor
- Learning guides to support the consolidation of your learning and as a reference tool
- Can be attended as a block of time or on separate days over a period of weeks
- Can be attended individually or with a group
- Culturally relevant and culturally safe learning
- Integration of learning into practice
- Post-placement support
- Linkages and knowledge sharing with specialist palliative care providers.
Reverse PEPA is available in Aboriginal and Torres Strait Islander settings, rural remote and residential aged care settings. A palliative care specialist travels to your place of employment to facilitate small group learning.

**On completion of the learning experience (workshop and placement), you will:**

- recognise how your own values and beliefs about finishing up/death and dying affect your responses and interactions with sick persons with advanced disease
- understand the principles of palliative approach to care and have an increased appreciation of finishing up/dying and death as a normal part of the life continuum
- have an awareness and understanding of diversity in cultural beliefs and the sensitivities involved in palliative approach to care provision
- identify the needs of those with a life-limiting illness and their family including care preferences, bereavement expression, cultural and spiritual requirements
- identify the role of your discipline in managing issues faced by sick person’s with a life-limiting illness
- appreciate the role of advocacy in palliative care
- identify practical ways to advocate for sick people, their family, palliative care services and staff roles
- identify the cultural beliefs and practices that should be included in care plans for sick people and their family
- use effective communication skills to increase understanding of palliative approach to care by sick persons, the family and the community
- identify services that can help to address the physical, psychological, social, cultural and spiritual concerns of sick persons and their family dealing with advancing disease
- prepare an information brochure or other media to explain the basics of palliative approach to care to sick persons, family and the community
- understand the legal requirements at the time death
- identify personal coping strategies to effectively manage the personal issues related to working in this field.
Pathway of Experiential learning in the Palliative Approach

The experiential learning program involves participation in a Workshop (4-8hrs) and Workplace Placement (2-5days).

After the Workshop is completed, you may want to establish better networks and communications with specialist palliative care services or experience the palliative care practice environment and delivery of the palliative approach.

**Opportunities are available** to participate in a 2-5 day observational placement in a specialised palliative care service. When a placement is finished and you return to your workplace, you will implement a project or activity to cement your new knowledge and skills. The activity may be a talk with co-workers about your experience and learning’s with PEPA or implementing a new palliative care resource or guidelines. It’s your decision. You will be advised of ongoing professional developmental activities and networking events.

Talk with your manager and ask if your workplace will approve your request to participate in a placement. You would be away from your workplace from 2-5 days. Please contact your PEPA Manager and enquire if there is opportunity for payment to backfill your position. An Aboriginal Project Officer may also be available to answer your questions.
At any time, if you are unsure about anything, please contact your PEPA Manager or PEPA Aboriginal Project Officer. Details on the PEPA website www.pepaeducation.com or on PEPA brochure. They are there to support you, whether that is to complete the application or have discussions with your manager about what the placement experience will bring to your workplace. The PEPA staff will also talk with you about your learning needs.

For those who have internet access, websites are listed in the Resources section. Two relevant website repositories (places were all information relating to specific topics are kept) are identified.

For those who have internet access, websites are listed in the Resources section. Two relevant website repositories (places were all information relating to specific topics are kept) are identified.

1. CareSearch is the Palliative Care Knowledge Network that uses health professional hubs for easy access to specific information about palliative care. My Learning will assist you to develop skills in identifying evidence and resources to provide validated care. http://www.caresearch.com.au

2. Australian Indigenous HealthInfoNet has comprehensive, up to date health facts, policies, promotional resources, practice resources, programs and projects and much more. http://www.healthinfonet.ecu.edu.au

We hope your participation in this program will be a rewarding and interesting experience and that your workplace and the people you care for will benefit from the knowledge, skills and confidence you develop throughout the program.
PEPA CONTACTS

PEPA has a team in each state and territory. If you have any queries or concerns about your placement application or registering your interest to attend a placement, please contact the PEPA Manager in your State or Territory. He/she will be able to direct you to the relevant information/person to address your queries.

PEPA MANAGER DETAILS

If there are no contact details here, you will find all the details you need on the website.

PEPA ABORIGINAL PROJECT OFFICER DETAILS

The PEPA Aboriginal Project Officer may also be a valuable resource for you.

Visit the website for the contact details of the PEPA team in your State or Territory.

Website http://www.pepaeducation.com
CORE COMPETENCIES IN THE PALLIATIVE APPROACH TO CARE WORKSHOP

PALLIATIVE APPROACH TO CARE WORKSHOP FOR ABORIGINAL & TORRES STRAIT ISLANDER HEALTH WORKERS/HEALTH PRACTITIONERS/COMMUNITY WORKERS & COMMUNITY

CORE COMPETENCIES:

Communication
• provide information and support related to palliative approach to care
• provide community education about the scope and services of the palliative approach to care
• demonstrate empathy and compassion when relating to sick persons with advanced and end stage illness, the family and the community

Advocacy
• identify and communicate cultural issues to be considered when implementing a palliative approach
• provide relevant information to service providers about cultural requirements for sick persons with an advanced and end stage illness, their family and community
• provide timely information to the sick person and the family about palliative care options

Coordination
• liaise between specialist palliative care services, the sick person, family and the community
• use problem-solving skills to negotiate service provision and to resolve issues as they arise
• liaise between the palliative care and primary health care teams to ensure seamless care for sick people and their family

Practice standards
• practice in accordance with legislative and ethical standards of palliative care and health worker/health practitioner practice
• observe and report palliative care needs of sick persons and their families
• evaluate, document and report the sick person’s response to palliative approach to care
• contribute to the palliative approach care team’s assessment process
In the workshop, we will work through one module at a time, completing all four modules. Most of the learning activities and thinking points are linked to Pop Arthur’s story presented in the comic book.

**PALLIATIVE APPROACH TO CARE WORKSHOP FOR ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH CARE WORKERS/ HEALTH PRACTITIONERS, COMMUNITY WORKERS & COMMUNITY**

**MODULE OUTLINES**

**Module 1: COMMUNICATION**
Explores the many dimensions of communication that are at the heart of a palliative approach to care

**Module 2: ADVOCACY**
Describes the scope of your role as an advocate for a sick person with advanced and end stage illness and their family to ensure cultural needs are integrated into care

**Module 3: FUNDAMENTALS**
Examines knowledge and skills needed to coordinate services and assist sick people and families to access appropriate palliative care services

**Module 4: PRACTICE**
Explains clinical aspects of a palliative approach to manage physical, psychological, social cultural and spiritual concerns

**ABOUT THE MODULES...**
Each module addresses a core competency in the palliative approach to care. There are four core competencies. Modules consist of **information, activities and thinking points**.

The thinking points are for you to consider your views, your values and feelings in relation to different palliative care situations. They are also designed to assist you to apply your learning into practice.

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Effective communication is at the heart of a palliative approach because it is a central skill for helping the sick person and family deal with the effects of chronic illness or advancing disease especially when the illness is unlikely to get better.

**COMPETENCY 1: COMMUNICATION**

- Provide information and support related to a palliative approach to care
- Provide community education about the scope and services involved in a palliative approach to care
- Demonstrate empathy and compassion when relating to sick persons with advanced and end stage illness, their family and the community

**MODULE OBJECTIVES**

On completion of this module, you should be able to:

- Use effective communication skills to increase understanding of the palliative approach to care for sick persons, the family and the community
- Identify services that can help to address the physical, psychological, social, cultural and spiritual concerns of sick persons and their family dealing with advancing disease
- Recognise how your own values and beliefs about finishing up/death and dying affect your responses and interactions with sick persons with advanced disease and their family.

**1.1 WHAT IS COMMUNICATION?**

Communication is the process between individuals and groups for sharing thoughts and information. The communication process involves:

- Verbal language, usually spoken, written, printed or displayed on a computer screen
- Non-verbal language, usually by gestures, facial expression, body movement and placement, eye contact, posture, hand and feet movement, use of space, signs and pace of delivering information are all methods for transmitting attitudes, beliefs and thoughts/feelings.
How people communicate can vary according to cultural differences. For example, traditionally Aboriginal and Torres Strait Islander peoples used visual images, storytelling and songs to communicate about culture, rather than written language. The language spoken also varies in different regions and clans groups. Today, English is not the first or even second language of many communities. These diverse language groups could easily be recognised as the primary need for alternative communication methods. Commonly, many Aboriginal and Torres Strait Islander peoples use body language, including facial expressions, gestures, and sounds as the primary communication tool.

**ACTIVITY**

List the different language groups that you know about. Identify the most common language used by the people in the community where you work.

**ACTIVITY**

Examine page 1 and 2 of the Pop Arthur comic book. For example, look at Frame 4 on page 1. Pop Arthur appears to be sitting-up perhaps ready to defend himself. His son Howie looks strong and is wanting to be assertive about the family decision. Then there is Steven holding his hat as if in respect, but he looks worried and maybe a bit frightened of the situation, while Pop Arthur’s wife Annette is standing behind her son Howie, and just looks sad.

**Describe the communication processes that you can see in the pictures where the family are gathered.**
ACTIVITY
Now examine Frame 5 and 6 at the top of page 2. How are the different people communicating? Summarise what you think is going on in Frame 5 and 6?

THINKING POINT
On pages 1 and 2, Pop Arthur is happily telling stories to his granddaughter Bertha, until the family arrive and someone suggests that she is too young to be there.

What are your views about children being involved when a family member is nearing the end of life like Pop Arthur? What makes you say this?
On page 3 look at Uncle Billy’s reaction to Pop Arthur’s decision that he does not want further treatment. Think about your role in supporting families like Pop Arthur’s. List some of the reasons why people in the same family may react differently to sad news or sorry business.

How can you support the family as well as the sick person considering that each family member is likely to react differently to the situation?
1.2 Principles of Supportive Communication

Supportive communication skills help you to:
• get a better understanding of the illness and its effect on the sick person and their family
• identify the sick person’s concerns and symptoms and why it causes distress
• understand the beliefs, needs and choices of the sick person and the needs of their family

Key strategies can be used when communicating with a person with life limiting illness and their family. The acronym PREPARED is way of practicing supportive communication.

PREPARE for the discussion, where possible:
• ensure facts about the patient’s clinical circumstances are correct
• try to ensure privacy and uninterrupted time for discussion
• mentally prepare
• negotiate who should be present during the discussion e.g. “Is there anyone else you would like to be here with you while we talk?”

RELATE to the person:
• develop a rapport
• show empathy, care and compassion during the entire consultation e.g. “This has been a tough time for you and your family...”
• broach the topic in a culturally appropriate and sensitive manner
• make eye contact (if culturally appropriate), sit close to the patient, use appropriate body language, allow silence and time for the patient to express feelings.

ELICIT patient and caregiver preferences:
• identify the reason for this consultation and elicit the patient’s expectations
• clarify the patient’s or caregiver’s understanding of their situation and establish how much detail they want to know
• consider cultural and contextual factors influencing information preferences.

PROVIDE information tailored to the individual needs of both patients and their families:
• offer to discuss what to expect, in a sensitive manner, giving the patient the option not to discuss it
• give information in small chunks at the person’s pace
• use clear, jargon-free, understandable language
• engage in active listening i.e. attend to the patient fully, reflect what you think they have said e.g. “If I’ve heard you right, you seem to be saying...”
• explain the uncertainty, limitations and unreliability of prognostic and end-of-life information e.g. “I know that often people expect doctors to know what is going to happen, but in truth we can often only take...”
ENCOURAGE questions and further discussions:

- encourage questions and information clarification; be prepared to repeat explanations
- check understanding of what has been discussed and whether the information provided meets the patient’s and caregiver’s needs
- avoid being too exact with timeframes unless in the last few days
- consider the caregiver’s distinct information needs, which may require a separate meeting with the caregiver (provided the patient, if mentally competent, gives consent)
- try to ensure consistency of information and approach provided to different family members, the patient and clinical team members
- use the words ‘death’ and ‘dying’ where appropriate.

ACKNOWLEDGE emotions and concerns:

- explore and acknowledge the patient’s and caregiver’s fears, concerns and their emotional reaction to the discussion e.g. “What worries you most about...?” or “What is your biggest concern at the moment?”
- be willing to initiate and engage in conversations about what may happen in the future and the dying process e.g. “Do you have any questions or other concerns?”
- respond to the patient’s or caregiver’s distress regarding the discussion, where applicable.

(foster) REALISTIC hope (e.g. peaceful death, support):

- be honest without being blunt or giving more detailed information than desired by the patient
- do not give misleading or false information to try to positively influence a patient’s hope
- reassure the patient that support, treatments and resources are available to control pain and other symptoms, but avoid premature reassurance
- explore and facilitate realistic goals and wishes and ways of coping on a day-to-day basis, where appropriate.

DOCUMENT:

- write a summary in the medical record of what has been discussed
- speak or write to other key health care providers involved in the patient’s care. As a minimum, this should include the patient’s general practitioner.
1.3 PREPARE FOR DISCUSSION ABOUT GOALS OF CARE AND ADVANCED CARE PLANNING (ACP)

Health care providers need to use effective communication that allows the sick person to talk about their needs and treatment options for when their illness gets worse.

For example, see page 3 of Pop Arthur’s story where the nurses explain to Pop Arthur about the worsening condition of his kidney function. This leads Pop to state his wish not to carry on with treatment. However, not everyone will understand or support the sick person’s decision as shown by Uncle Billy’s reaction on page 3. This can be their way of coping with sad news and expressing fear for what is ahead.

Many people are not used to talking about their personal feelings or expressing their concerns, beliefs, needs and choices and may find conversations about sad/bad news to be very difficult.

To provide appropriate support for families like Pop Arthur’s, it is also important that you recognise how your personal feelings can influence your communications. This self-awareness supports your resilience and self-care.

**THINKING POINT**

Take a quiet moment to think about your feelings. Think about how you have reacted and responded to finishing up/dying and death.

If you haven’t experienced the death of someone close to you, consider how it would make you feel. What are your thoughts and feelings about finishing up/dying and death?
Think about how others in your family react and respond to finishing up/dying and death. Consider the factors that contribute to your thoughts and beliefs around finishing up/dying and death.

What has been your experience of finishing up/death? Thinking about these experiences, have they been good or bad?
What are your feelings when talking to a sick person with advanced disease or at the end stage of their illness?

What causes you the most difficulty when talking to a sick person who has an advanced or end stage illness?
1.4 OPEN CONVERSATIONS FOR END OF LIFE CARE PLANNING OR ADVANCE CARE PLANNING (ACP)

CARE PLANNING/ADVANCE CARE PLANNING

Historically, care plans have been completed for people requiring ongoing care and identified goals of care for the health care providers. Today, health care interactions are evolving to patient centred care that involve the sick person and their family’s concerns, beliefs and needs. This includes care plans that advise of people’s choices that reflect respect and dignity for people and prevents unnecessary suffering.

Ask the sick person:
» ‘Who is the right person to talk to about...?’ and
» ‘Is there other people that you want involved?’

Asking will allow the sick person to provide that information.

It is important to note that care planning may look different for different families. It may include the sick person, family spokesperson or other key people and health care providers. Awareness and acceptance of these differences is important. For example, see frame 2 at the top of page 4, where Pop Arthur makes his wishes (beliefs and choices) known and tells his son Howie that he has to take charge of things.

1.5 ENGAGE PEOPLE BY ASKING THE RIGHT QUESTIONS

The right questions are open ended that encourage the person to talk about their preferences for care. For example:

- “Where would you like to be?”
- “What are you hoping for now?”
- “What is important to you?”
- “Is there anything that you need to do?”
- “What would you like to do in the time that is left?”

CHECKING AND CLARIFYING

A sick person’s goals can change as their condition progresses. It is important to check your understanding and their understanding of the needs and requests over time.

REMEMBER if you are aware that there is someone else that should be involved in this conversation, it is important to make sure they are included.
1.6 FAMILY MEETINGS

A family meeting is the care team, the sick person and their family members coming together to have a yarn, generally to share important information.

It enables the sick person and family to become members of the care team, to clarify their understanding of the diagnosis (illness) and prognosis (likely outcome). The care team actively involves the family to discuss information that answers questions or explains information that family members may not be familiar with or that cause concern or worries.

In these meetings, your role will vary. Often it may be as a cultural broker for family members and as an advocate for the palliative approach to care and services.

Family members maybe shocked with any new information. They may find it difficult to ask all the questions they have or they may be reluctant to discuss personal family business with outsiders. If the family is having challenges after receiving critical information, it is a good time for you to ask some clarifying questions of the care team. This can help family members to process information and it allows information to be available when they are ready.

Family meetings:

• require a skilled facilitator (usually the Doctor)
• may require an interpreter/translator
• can be initiated at the family’s request or by the palliative care team
• encourage forward care planning (advance care plans)
• provide a clearer picture of the goals of care and options for symptom relief
• need to be mutually beneficial for the sick person and their family
• have their proceedings documented.
1.7 FAMILY DYNAMICS AND DECISION MAKING

Read page 6 and 7 of Pop Arthur’s story and describe what is going on.

**ACTIVITY**

It is common for the men and women to discuss things in separate groups. How can you help this process?

---

**ACTIVITY**

Why might Billy be angry, insisting that Pop needs to ‘toughen up’?
ACTIVITY
How does reminiscing about others who have already finished up/passed on influence the family’s views about Pop Arthur’s situation?

ACTIVITY
List some of the fears expressed by Pop Arthur’s family.
ACTIVITY
List the local services in your community that could support a sick person and their family to be at home if they wish.

CONCLUSION
Well done! You have completed Module 1

In this module we have explored different aspects of communication that are vital for helping sick people and their family with supportive and palliative care needs. Referring to examples presented in Pop Arthur’s comic book enabled you to examine different forms of verbal and non-verbal communication and to consider how family members react to sad news. We identified principles of supportive communication and skills for helping the sick person and their family with goal setting and care planning. You also had the opportunity for some personal reflection and ‘thinking’ about finishing up/dying and sorry business.
MODULE 2 - ADVOCACY

SPEAKING UP ABOUT CULTURAL ISSUES

This brief module helps you apply further communication skill in your role as cultural broker and advocate for sick persons, families, local community and health care services and staff.

COMPETENCY 2 - CULTURAL BROKERAGE & ADVOCACY

• Identify and communicate cultural issues to be considered when implementing a palliative approach to care
• Provide relevant information to service providers about cultural requirements for a sick person with an advanced and end stage illness, their family and the community
• Provide timely information to the sick person and their family about palliative care service options

MODULE OBJECTIVES

After completing this module you should be able to:

• understand the role of advocacy in palliative approach to care
• describe practical ways for health care providers to advocate for sick persons, families, palliative care services and staff
• identify the cultural beliefs and practices that should be included in care plans for sick persons and their families.

DEFINITIONS

Cultural Brokerage is the act of bridging, linking or mediating between persons or groups of different cultural backgrounds for the purpose of reducing conflict, increasing understanding and producing change.

Advocacy is representing the sick person and their family to ensure their cultural integrity is protected and other health care providers are aware of the sick persons and their family’s concerns, beliefs, needs and choices. Advocacy also reflects the need to clarify and endorse the organisation’s staff, roles and responsibilities to the sick person and their family.

Advocating for the sick person and their family is a responsibility you should only take on with consent. Alternatively, you can support the family’s self-advocacy by ensuring they have sufficient support and information about processes and services.
2.1 CULTURAL BROKER & ADVOCATES

**ACTIVITY**

Refer to Pop Arthur’s story on pages 6 and 7 where the family are reminiscing about people they knew who had a bad experience at the end. How could a cultural broker/advocate have helped Glenis and Uncle’s Laurie and Charlie, to finish up/die where they wanted to be?

Glenis

Uncle’s Laurie

Charlie

**ACTIVITY**

List some of the important cultural beliefs and practices of your local community that the palliative approach team need to know about.
2.2 CULTURAL BELIEFS AND PRACTICES VARY BETWEEN AND WITHIN COMMUNITIES.

People identifying as Indigenous Australians represent many different cultural beliefs according to where they were raised, family influences and life experiences.

**ACTIVITY**

Use the following table to identify the particular beliefs and practice of the patients and families in your community or work setting

**Table 2 Cultural beliefs and practices**

<table>
<thead>
<tr>
<th>FOCUS</th>
<th>SPIRITUAL VALUES</th>
<th>CULTURAL KNOWLEDGE</th>
<th>PSYCHOLOGICAL BELIEFS</th>
<th>PHYSICAL</th>
<th>SOCIAL/FAMILY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key points</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Behaviour or practices</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Impact on health care</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Impact on end-of-life care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Customs for after life care</td>
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</tr>
</tbody>
</table>
ACTIVITY

List some strategies that will help you to communicate about cultural issues with the local palliative care services.

2.3 ADVOCACY

Many people and families facing serious illness are likely to feel vulnerable and perhaps overwhelmed by the palliative care environment. Health care providers have an important role in communicating to the sick person and family about palliative care services, the staff and the options.

THINKING POINT

How do you currently help sick persons and families with advanced and end stage illness get access to health care services they need?
What aspect of the advocacy role are you comfortable with?

What aspect of the advocacy role worries you?

What can you do to promote cultural safety in palliative care services?
CONCLUSION

Congratulations! You have completed module 2

In this module, we have considered your role as cultural broker for sick persons and their family who need palliative care services. We have examined how advocacy can be used to promote cultural safety, and the importance of communication and knowledge of local services to support people who want to stay in their home.
MODULE 3 - FUNDAMENTALS OF THE PALLIATIVE APPROACH TO CARE

This module will help you develop knowledge and skills needed to inform the family about the palliative approach to care and to assist sick people and families to access appropriate services.

COMPETENCY 3 - COORDINATION

• Liaise between the specialist palliative care services, the sick person, families and the community
• Use problem solving skills to negotiate service provision and to resolve issues within your scope of practice as they arise when providing palliative approach to care
• Liaise between the palliative care team and primary health care team as a means to facilitate seamless care for sick persons

MODULE OBJECTIVES

After completing this module you should be able to:

• understand the principles of palliative approach to care
• prepare an information brochure or other media to explain the basics of palliative approach to care for sick persons, families and the community
• understand the various services involved in providing palliative approach to care and how to access these.
3.1 COORDINATION & ORGANISATION

A key part of your role in the palliative approach to care is about collaboration with the multi-disciplinary team (MDT) to ensure the health care providers are aware of needs and concerns as they occur. You will work with the MDT to support and ensure services are timely and relevant to the sick person and their family according to their needs. Regardless if you are organising, coordinating or collaborating, the sick persons and the family needs are at the centre of your care.

Often the lead service (specialist palliative care, primary health care, cancer care) may be coordinating. It is good for you to open communications with everyone, especially the coordinator. This is the first person you will contact as needs change or if you have concerns.

If you have been providing services to this family for some time, identify this to the MDT and advise of previous links to supports and the existing arrangements.

Having the diversity of a larger team to support the sick person and the family means the wealth of knowledge about resources and supports will be greater. Advising or seeking input from the MDT will also provide you with greater networking and resources.
3.2 KEY PRINCIPLES OF A PALLIATIVE APPROACH TO CARE

1. A palliative approach is health care provided for sick people of all ages, who have a chronic illness or advanced disease with little or no possibility of a cure.
2. The primary goal of a palliative approach is quality of life for the individual until their finishing up/death.
3. A palliative approach aims to protect sick persons and families from unnecessary suffering by treating, relieving and reducing symptoms associated with advanced illness.
4. The palliative approach always includes the emotional and supportive care of the sick person and the family.

3.3 KEY POINTS OF A PALLIATIVE APPROACH TO CARE

- A palliative approach is not limited to a facility, but can be implemented in any location including a family home, aged care facility, in the community, a hospital or palliative care unit.
- A key factor influencing the place of palliative care is where the sick person and the family want to be.
- A palliative approach is appropriate at anytime during a person's illness when their symptoms become a worry.
- The palliative approach is provided by a multi-disciplinary team of health care providers that work with the sick person, their primary carers and other members of the family.
- The palliative approach embraces the physical, emotional (psychological), social, cultural and spiritual concerns of the sick person and their family.
- The specialist palliative care team can directly manage the person's symptoms or provide advice to the primary health care team, community teams and other service providers.
- The scope of a palliative approach enables supportive care for the sick person and for their family, extending through the time of grief and bereavement, if this is required.
- When symptoms/pain changes, it's important to tell someone in the palliative approach care team. These changes can happen quickly and often-new medications may be required to effectively treat the pain.
3.4 PALLIATIVE APPROACH CARE TEAM IS MULTI-DISCIPLINARY

There can be many health care providers in the palliative care team, as Diagram 1 illustrates. While illness takes a certain path (trajectory), its effects can be different for each sick person and family, many factors impact on this. The care team will depend on the sick person’s needs and the family’s resources and requests for assistance.

The only consistent factor in multi-disciplinary care team is that the sick person and the family are always in the centre of care.

DIAGRAM 1

Adapted from the Palliative Care Council South Australia http://www.pallcare.asn.au

Health care providers delivering palliative care services come from diverse faiths, spiritual traditions, and cultural backgrounds. The commonality of such diversity is in the peoples values. Values including compassion, kindness, respect for life and respect for others with different beliefs and values.
**ACTIVITY**
Who are the palliative care service providers accessible to your community or the place where you work?

Complete the following table by filling in names, services and contact details of the palliative care providers in your area. The information could be a useful reference for your future work.

**Table 3 - Identifying palliative care staff, services and contact details**

<table>
<thead>
<tr>
<th>PALLIATIVE CARE HEALTH CARE PROVIDER</th>
<th>PALLIATIVE CARE SERVICES PROVIDED</th>
<th>CONTACT DETAILS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Director Palliative Medicine</td>
<td></td>
<td></td>
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<tr>
<td>Clinical Nurse Manager/Consultant</td>
<td></td>
<td></td>
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<tr>
<td>Consultant in Palliative Medicine (specialist)</td>
<td></td>
<td></td>
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<tr>
<td>Medical Registrar (Dr) (Graduate, Intern, Resident, Specialist/GP, Resident, Registrar)</td>
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</tr>
<tr>
<td>General Medical Practitioner (GP)</td>
<td></td>
<td></td>
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<tr>
<td>Nurses - Hospital (EN, RN)</td>
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<td></td>
</tr>
<tr>
<td>Nurses - Community (EN, RN)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PALLIATIVE CARE HEALTH CARE PROVIDER</td>
<td>PALLIATIVE CARE SERVICES PROVIDED</td>
<td>CONTACT DETAILS</td>
</tr>
<tr>
<td>--------------------------------------</td>
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</tr>
<tr>
<td>Aboriginal or Torres Strait Islander Hospital Liaison Officer&lt;br&gt;(person centred holistic care that involves family)</td>
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<td></td>
</tr>
<tr>
<td>Aboriginal or Torres Strait Islander health worker - Community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal or Torres Strait Islander health worker palliative care specialist</td>
<td></td>
<td></td>
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<tr>
<td>Cultural broker or advocate</td>
<td></td>
<td></td>
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<tr>
<td>Volunteer Coordinator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist&lt;br&gt;(assess/restore/maintain function, skill development)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pastoral Care Worker&lt;br&gt;(caring professional that includes spiritual care)</td>
<td></td>
<td></td>
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<tr>
<td>Spiritual Care Worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative Care Health Care Provider</td>
<td>Palliative Care Services Provided</td>
<td>Contact Details</td>
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<tr>
<td>-------------------------------------</td>
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<tr>
<td>Grief and Bereavement Counsellor</td>
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<tr>
<td>Local Pharmacists (chemist)</td>
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<td></td>
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<tr>
<td>Volunteers in Community</td>
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<tr>
<td>Volunteers in Hospital</td>
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<tr>
<td>Advance Care Planning Coordinator</td>
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<tr>
<td>Physiotherapist (assess movement, assist to improve)</td>
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<tr>
<td>Dietician (nutritional information and resources)</td>
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<td></td>
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<tr>
<td>Interpreters (language)</td>
<td></td>
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<tr>
<td>Other staff</td>
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</tbody>
</table>
In Pop Arthur’s story, Terry the primary care nurse seems to be coordinating the services, and getting equipment like wheelchairs and hospital beds organised (see page 11). This could also be part of a health worker’s role. It is important to collaborate with the coordinator as often it is the Aboriginal health worker who has the most consistent contact with the sick person and the family and can identify when changes occur or medical aids can help. Make sure any matters are always discussed with the sick person to ensure that the medical aids are practical, acceptable for use and will be helpful.

ACTIVITY
Find out what equipment is available in your community to help sick persons who have advanced and end stage illness to be cared for at home. Determine where the equipment can be obtained and who can pay for any costs if needed.

Table 4 Home care equipment in your community

<table>
<thead>
<tr>
<th>EQUIPMENT TYPE</th>
<th>ORGANISATION LOANING EQUIPMENT</th>
<th>CONTACT DETAILS/ PHONE</th>
</tr>
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<tbody>
<tr>
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</tbody>
</table>
3.5 WHO CAN BENEFIT FROM A PALLIATIVE APPROACH?

A palliative approach focuses on relieving pain and suffering to improve the quality of life or to live as well as possible for those with a life limiting illness.

This holistic approach includes care and supportive comfort for families and caregivers (and may extend to the community) during illness and bereavement. It is suitable for people of any age, regardless of the type of illness they have. For example, a palliative approach can be beneficial for people with health needs and problems associated with:

- advanced renal disease
- advanced cardio-vascular disease
- end-stage liver disease
- end-stage respiratory disease
- any type of cancer
- HIV/AIDS
- motor neurone disease
- end-stage dementia
- advanced degenerative conditions and changes
- older people dying as a consequence of the aging process.

**ACTIVITY**

List the illnesses of the characters in Pop Arthur’s story had

<table>
<thead>
<tr>
<th>Pop Arthur’s illness</th>
<th>Glenis</th>
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</thead>
<tbody>
<tr>
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</table>

<table>
<thead>
<tr>
<th>Uncle Laurie</th>
</tr>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>Nana Patsy</th>
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</table>
ACTIVITY
Refer to pages 3, 4 and 6 of Pop Arthur’s story. List the problems and health concerns facing Pop Arthur and this family.

ACTIVITY
Explain why a palliative approach may help Pop Arthur and his family at this stage. List some of the palliative care services that you could recommend.

The principal goal of a palliative approach is to promote the best quality of life for the sick person and provide supportive comfort for their family.

Improving the quality of life for sick people and supportive comfort for their family is not a simple process because quality of life has many different elements, which includes physical, social, cultural, spiritual and emotional changes. Quality of life is defined by each person in unique ways and can change over time.

A useful exercise is to consider what contributes to your own quality of life and that of you family and friends.
THINKING POINT
List the things important to your quality of life.

• How does this list compare with other people in your family, work colleagues and friends?

ACTIVITY
Refer to Pop Arthur’s story. What things do you think might improve (a) Pop Arthur’s quality of life, (b) the various family members’ supportive comfort?

(a)

(b)
3.6 TALKING ABOUT PALLIATIVE APPROACH TO CARE WITH FAMILIES AND COMMUNITIES

Helping families understand what is on offer from palliative care is an important part of a health care provider’s role. However, it takes some thought to explain palliative approach to care to people outside of the health care system.

The word palliative in health care is from ancient French and Latin languages meaning to cloak or cover. Some perceptions might be that palliative care covers or takes away the sick person, while others may understand that palliative care covers effects of a disease by minimising its signs and symptoms. It is not surprising that people in the community do not readily understand the word palliative unless they have academic health care knowledge.

**ACTIVITY**
Suggest how you might explain palliative care to the people in your community.
ACTIVITY

Search out existing brochures on palliative care that are available in the place you work, and see if these would be suitable for your community. Some examples of good information brochures are listed below for your review.

- ‘It’s the beginning of your health care dreaming’ produced by Victoria Aboriginal Community Controlled Health Organisation (VACCHO)
- ‘Palliative Care’ produced by Kimberley Palliative Care Service
- ‘What is Palliative Care’ Factsheet by Cancer Council NSW

Other examples of good end of life care resources

- ‘Bessies Story’ booklet produced by The Cancer Council of Western Australia
- ‘Palliative Care for sick lungs’ Book/flipchart by Health and Palliative Care, Northern Territory
- Taking control of YOUR health Journey Booklet Respecting Patient Choices Advance Care Planning, Austin Health Heidelberg Victoria
- Understanding Morphine booklet produced by Mt Isa Palliative Care
- Wanem Morphine (creole) booklet produced by Cancer Council Queensland
CONCLUSION

Well done. You have completed Module 3

In this module, we have discussed a palliative approach and examined its primary goal of the best quality of life for the sick person and supportive comfort for the family. We examined ways you can compile information about palliative care services and equipment that are accessible to sick people, families and your local community.
MODULE 4- THE PRACTICE OF A PALLIATIVE APPROACH TO CARE

The activities in module four will develop your understanding of the principles of assessment and clinical interventions for sick people with physical and emotional issues associated with advanced and end stage illness.

COMPETENCY 4 - PRACTICE

• Observe and report palliative care needs of sick persons and families
• Evaluate and report sick person’s response to palliative approach
  • Contribute to the palliative care team’s assessment process
• Document and report assessment data and responses to palliative approach to care
• Practice in accordance with legislative and ethical standards of palliative care and health worker practice

MODULE OBJECTIVES

After completing this module you should be able to:

• identify the care needs of sick persons and families
• contribute to the assessment of the sick person’s physical, psychological (emotional), social, cultural and spiritual care needs
• contribute to the implementation of palliative interventions for symptom control
• facilitate appropriate physical, emotional, social, cultural and spiritual support as required by the family
• understand the legal requirements at the time death.

In module 3, you learnt that a palliative approach is not limited to a specific diagnosis like cancer, but can be helpful for people with a wide range of chronic, advanced and life-limiting illnesses.
4.1 PALLIATIVE APPROACH TO SYMPTOM MANAGEMENT

You have learnt in module 3 that the principal goal of a palliative approach is to optimise the sick person’s quality of life and to provide supportive comfort for the family.

Achieving this goal starts with gathering information about the sick person’s main worries (concerns), whether these are physical or emotional, social, cultural, spiritual or something else.

Some of the most common physical worries or symptoms of advanced illness include:

• pain
• fatigue - loss of energy
• dyspnoea - difficulty breathing
• coughing - dry or productive (flemmy)
• anorexia - loss of appetite
• difficulty swallowing
• constipation (blocked-up)
• diarrhoea (belly runs or runny belly).

Some of the most common psychological (emotional) symptoms that occur with advanced illness include:

• emotional distress
• sadness
• fear
• anxiety
• depression.

Some other common symptoms that can indicate other social worries or cultural and spiritual distress include:

• insomnia and chronic tiredness
• nightmares
• restlessness
• confusion or disorientation.
4.2 UNDERSTANDING SYMPTOMS

Careful assessment is the best way to gather information about a sick person's symptoms.

All health care providers contribute to the assessment of a sick person’s condition. Your role is to observe changes in the sick person’s condition, ask appropriate questions to find out more, document your findings and if appropriate pass on the information to the relevant health care providers. For example, refer to page 11 of Pop Arthur’s story.

Other health care providers might raise concerns with you to see if you have noticed any similar concerning factors or to clarify if matters may be related to cultural factors.

ACTIVITY
Refer to page 11 of Pop Arthur’s story, where Howie is telling Nurse Terry about the changes to Pop Arthur’s condition. Notice that Howie is referring to his notes.

What are Pop Arthur’s main physical symptoms reported by Howie to Nurse Terry?
4.3 YOUR ROLE IN ASSESSMENT - GUIDELINE FOR ASSESSMENT COMMUNICATION

Listen to the sick person and the family’s story about the sickness and symptoms:

- look for contributing factors or situations that seem to make the symptoms worse, for example: movement, eating, distress or fear
- ask about the sick person’s treatment, medications and other therapies they are using, including home remedies
- ask if the sick person has accessed a traditional healer for healing practices or traditional medicines or if they wish to
- talk to the primary carer about changes, symptoms or moods they have noticed
- ask how the carer is coping
- observe for signs and symptoms of changes in the sick person physical condition, this may include, eating, breathing difficulties, skin colour changes, pulse rate and body temperature
- ask the sick person ‘what is worrying them the most?’
- check for other changes in the sick person’s and family’s needs
- ask about how the medications are working
- ask are they getting to the toilet or finding it difficult to sit down and get up from toilet

4.4 SYMPTOM ASSESSMENT - PAIN

Pain is a common symptom associated with advanced illnesses and probably the one that initially causes most distress. The aim of pain assessment is to ensure the most appropriate treatment or intervention is given. Your observations and assessment of the sick person’s pain is important to the management of pain.

Find out about the sick person’s pain, questions to ask:

- “Where is the pain?”
- “What makes it worse or better?”
- “What are you doing to ease the pain?”
Determine the type of pain:

Ask the sick person to describe the pain, for example, you could ask: “Is it a shooting pain, stabbing pain, pricking, burning, or like a cramp?”

• these different types of pain are caused by different systems in our bodies, often requiring different treatments. Being able to clearly define the type of pain will assist the palliative care multidisciplinary team (MDT) in determining options for pain relief.

Determine the severity of the pain:

• there are several visual pain assessment tools, an example is the face pain scale, it is useful for most people
• alternatively you can ask the sick person to rate their pain on a number scale from 0 = no pain to 10 worst pain imaginable
• determine any psychological worries or cultural and spiritual concerns that may influence the sick person’s pain experience
• record your observation and assessment information so it is available to other health care providers.

Pain Assessment Tools

Below are 2 pain assessment tools, the Face Pain Scale & Numerical Scale
4.5 TREATMENT OF PAIN

Pain management includes pain relieving medications like Paracetamol, Aspirin, Codeine and Morphine. The usual practice for pain management is to start with the milder medication and build up to the stronger ones like Morphine for severe pain or as the condition worsens.

Pain management requires a holistic approach that integrates pharmacological, medical and non-medical treatments:

For example, the effectiveness of medication may be improved if the sick person feels emotionally supported and that their cultural and spiritual needs are met.

• emotional support and counselling is helpful because pain is intensified and harder to deal with if a person is feeling anxious, worried, fearful, lonely or depressed
• listening, answering the person’s questions, normalising and explaining what symptoms are expected and aligning that with what is actually happening may help relieve some worries
• other interventions to help the sick person in pain can include encouraging deep breathing and relaxation techniques, using distraction, like music, imagining, having visitors tell stories, and advising family how they can help with pain management
• be aware for many Aboriginal and Torres Strait Islander people psychosocial, cultural and spiritual matters may be tightly interwoven.

Emotional support strategies to help manage symptoms include:

• somebody always being with the sick person
• keeping a happy and harmonious environment
• giving time for the sick person to tell their stories
• providing time to listen to their worries
• addressing concerns
• referring to counsellor or psychologist (if necessary)
• encouraging everyone to visit, for some reminiscing and stories
• ensuring the sick person is included not hidden away in a distant room.

Physical methods to help manage symptoms include:

- touching, stroking, massage, rocking
- ice and heat for some areas
- deep breathing
- positioning for more comfort
- damp or cool washer
- mouth swabs
- visiting a special place or having something from the special place.

Cognitive methods (i.e. how we think about things) to help manage symptoms include:

- family gathering
- distraction such as music, radio, TV or sharing stories
- imagining pleasant scene and happy memories
- support the sick person and family in addressing any unfinished business.

Cultural, spiritual or religious practices that can help manage symptoms include:

- family friends and the community to come to visit
- being accessible for family and visitors
- traditional healing rituals or methods (WHO 2004)
- various family and cultural practices
- being respectful and accepting of others’ beliefs, concerns and needs
  » others’ lack of acceptance of beliefs, concerns and needs will impact on all patient interactions and pain levels
- ask open ended questions and listen to the responses to allow the exchange of information needed
- provide supportive information about practical ways family members can support/help the sick person. This is a vital for family members to know
- prayer.
Many Aboriginal people and Torres Strait Islander people believe in the cyclic concept of life, indicating an ongoing path, Life-Death-Life. A knowing that finishing up and the end of life is an important pathway. This time is respected culturally with rituals and ceremonies and called Sorry Business/Sad news.

For many with life limiting illnesses they would rather spend the end of their life in a familiar environment, being cared for respectfully, surrounded by family and visitors (also being respected), being able to participate in rituals without justification. The spirit becoming stronger for the journey as every person who visits is showing respect, bringing acceptance and love. This accepting, inclusive open honest environment respects and supports the end of life care path and finishing up. When choice is enabled this path is filled with empowerment, strength, courage and wisdom.

For some a respectful pathway and environment along with these beliefs changes the psychological and cognitive matters. Below is the emotional symptoms we viewed earlier, in *italics* is the emotional symptoms identified with strong cultural beliefs linked to spirituality.

- emotional distress
- sadness
- fear
- anxiety
- depression
- anticipatory grief & loss
- connectedness
- sense of worth
- comfort
- supported / dignified.

For many families, key members have specific preparations (before and after finishing up) to be undertaken to assist through this journey.

There may come a time when a sick person does not have anyone to be a carer, or family supports nearby, they may have a complicated care path, they may not have been given the information about the end of life options or engaged about their choices leaving few options unless admitted to a service. For others the physical challenges and symptoms may be too great for home and care within a service is needed or care may be provided at home but strong spiritual beliefs may impede finishing up/death inside the home.

For those that require admission to a specialist palliative care service or hospital ward for an undetermined amount of time, it is important that supportive advocacy is available for the sick person and the services staff.
Yarning with family to help them to support:

It is natural for family to know how to care for each other, although many emotions can cloud judgement. If family members are unsure of ways to make the person comfortable, reassure them and talk them through the practical cares:

• encourage everyone to talk, talk talk! Worries quickly become anxieties if not discussed, clarified or addressed
• this is sad business but now is the time for forgiveness, love, sharing and togetherness
• often sick people’s physical abilities deteriorate and it becomes difficult to leave the house. Catch the sick person up with all the goings on. Still feeling connected to the world is important
• it is ok to be yourself, greet as you normally would, have a good yam, use humour, laugh and cry
• provide physical contact by light touch or holding hands
• encourage family and friends to visit and yam with the sick person
• listen to the sick person’s fears/concerns, needs and wishes/choices
• give information sensitively about the dying process at the appropriate time, to the appropriate people
• moisten the sick person’s lips, mouth and eyes (wet washer or mouth swabs) or a cool mouth rinse or wipes
• keep the sick person clean dry and cool or warm
• be aware, some family members may show no interest in engaging with the sick person, it simply may be kinship avoidance relationship and it may not be appropriate for them to engage with the sick person.

Help provide cultural and emotional support by:

• sharing family ways with the palliative care MDT
• addressing queries the palliative care MDT may have
• being accepting of people and their ways
• give the sick person time to talk about their life, concerns or worries
• listen with empathy
• be prepared to talk and listen about spiritual and cultural matters
• affirm the beliefs and life of the sick person
• be understanding of people’s reaction to loss and grief
• be prepared to take-on people’s reactions, for example anger, being demanding
• you don’t always need to be with the sick person, provide support to other family members, including the children.

Other cultural ways:
• respect everybody
• use manners
• don’t speak all the time, listen
• respect Men’s Business & Women’s Business
• share information with key family members
• don’t overuse touch
• talk to those you don’t know
• if there is visitors you may need to wait until it is your time, you can yam with others about how they are
• be mindful of avoidance behaviours
• be mindful of cultural ways.

Practical matters to address with family/carer/health care providers:
• ensure the sick person and family have the option to access to a local healer, spiritual guide or religious minster whichever is their preference
• ensure the key family members are aware of current and any other milestones left in the care path
• prepare for bladder and bowel incontinence with either pads or plastic bed sheets
• consult about when non-essential medications can be stopped, for example cholesterol medications
• consult with health care providers about essential medications, for example pain relief medications, anti-diarrhoea or nausea medications
• how to keep the skin clean (bed baths)
• how to help the sick person to move and reduce the pressure and risk of sores
• support key family members with implementing the Advance Care Plan
• protect the sick person from over enthusiastic evangelists or ‘helpers’.

Practical comfort measures:
• keep the sick person clean dry, cool or warm
• keep the skin clean (bed baths)
• if practical, help the sick person to move and reduce the pressure and risk of sores
• have water iceblocks/ice cubes to wet the mouth
• keep the mouth moist
• assist/support others
• maintain the sick person’s dignity.
4.6 ASSESSING AND MANAGING OTHER COMMON SYMPTOMS

Table 5 identifies the usual interventions that may be prescribed for some of the common symptoms that a sick person can experience as their condition gets worse. The third column in the Table lists examples of home care remedies and interventions that may be used by some people and families. You can add to the list of home care remedies when talking to the people about their particular methods.

**It is important to inform the palliative care providers about a patient’s use of home remedies or traditional medicine to ensure they compliment or are compatible with other treatments.**

**Table 5 Common symptoms, treatment and suggested home care remedies**

<table>
<thead>
<tr>
<th>SYMPTOM OR PROBLEM</th>
<th>TREATMENT</th>
<th>HOME CARE REMEDIES, EXAMPLES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constipation (blocked-up)</td>
<td>Laxative preparation</td>
<td>Encourage frequent small drinks during the day</td>
</tr>
<tr>
<td></td>
<td>Exercise as much as is possible</td>
<td>Give foods that are easy to eat and known to encourage bowel actions, e.g. Kiwi fruit, prunes and prune juice, apricots, pears, dates</td>
</tr>
<tr>
<td>Diarrhoea (belly runs)</td>
<td>Anti-diarrhoea drugs may be given</td>
<td>Increase fluid intake to replace the loss</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Avoid sugary drinks, coffee, alcohol, raw foods, cold foods, fatty foods and high-fibre foods</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Encourage normal eating</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Add food that help reduce diarrhoea, e.g. potatoes, and rice</td>
</tr>
<tr>
<td>Symptom or Problem</td>
<td>Treatment</td>
<td>Home Care Remedies, Examples</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Nausea and vomiting (spuing)</td>
<td>Antiemetic drugs may be given</td>
<td>Encourage the sick person to eat, but not to force them, as their body may not be able to digest the food</td>
</tr>
<tr>
<td></td>
<td>Frequent oral hygiene</td>
<td>Offer smaller meals of whatever the sick persons asks for</td>
</tr>
<tr>
<td></td>
<td>Swab mouth with weak salt water or sodium bicarbonate</td>
<td>Let the sick person suck on fruits such as pineapple, oranges or passionfruit</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Encourage to have a regular mouthwash and teeth cleaning</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Use a weak salt water (pinch of salt in water) or sodium bicarbonate 1/2 teaspoon in a glass mouthwash</td>
</tr>
<tr>
<td>Breathing difficulties</td>
<td>Oxygen may be administered (although it is not always beneficial – talk with health care providers)</td>
<td>Help the sick person sit in the best position</td>
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<tr>
<td></td>
<td>Other medication to open airways maybe given depending on the person’s condition</td>
<td>Use extra pillows or cushions for back support</td>
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<tr>
<td></td>
<td></td>
<td>Open windows to allow fresh breezes</td>
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<tr>
<td></td>
<td></td>
<td>Assist to sit outside if possible</td>
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<tr>
<td></td>
<td></td>
<td>Fan with newspaper, or clean cloth or electric fan</td>
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<tr>
<td></td>
<td></td>
<td>Avoid cooking or smoking near the sick person</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Plan activities like toileting, washing to limit exertion</td>
</tr>
<tr>
<td>Coughing</td>
<td>Sometimes medication can be helpful – consult with health care providers</td>
<td>Local soothing mixture e.g. honeys and lemon, steam inhalation with eucalyptus leaves</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Give plenty of water to drink</td>
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</tbody>
</table>
ACTIVITY
Refer to Pop-Arthur’s story up to page 14. How would you describe his emotional, cultural and spiritual state? Is it good or troubled? What makes you say that?

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ACTIVITY
What is going on with Pop Arthur to contribute to your assessment of his emotional, cultural and spiritual state?
**THINKING POINT**

It appears that Pop Arthur is comfortable at home with his family around. How can telling Bertha about what happens to dogs and magpies that die and where Nana Patsy is buried can help Pop Arthur prepare himself?

Upholding cultural practices including spiritual support becomes even more important during the end-of-life journey.

**ACTIVITY**

Refer to Pop Arthur’s story. Describe some of the cultural practices that are shown in his story.
4.7 END-OF-LIFE CARE

Wherever possible, it is important to have prepared an advance care plan (See Module 1). Refer to this plan with the sick person and their family and ensure the palliative approach care team is aware of the sick person’s concerns, beliefs, needs and choices from the start, and continue to provide them relevant information like the family’s specific beliefs and needs. As the milestones commence bringing the end of life near, its important the care team is aware (they may have built a supportive relationship and their support may be important). Continue to share signs and changes with the family about the illness path, making sure key family members are aware of the closeness of finishing up. They will let the other family know.

Many cultural groups and religions will have signs meaningful to them to advise that life is nearing an end:

• for many Aboriginal people in the days before finishing up, they receive spiritual visitors. Some call this deathbed visions. The spiritual visitors, often those who have already finished up/died, visit to advise they and many others are waiting for their arrival
• for many Torres Strait Islanders in the time before finishing up, they may mimic their totem. A totem is an animal or bird that represents family groups or the person.

Signs and symptoms commonly occurring at the end-stage of an illness:

• peripheral shutdown seen as changed skin colour which may look patchy
• loss of appetite, the sick 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.

Many of these signs and changes indicating the end stage of an illness can be managed with medical interventions, psychological and spiritual care.

REMEMBER, it is vital that the family members are aware that the sick persons life journey is near the end.

Avoiding this imperative awareness will ensure someone is blamed for the loss. This will impede the grieving process for family and also cause stumbling blocks for others that may require care in the future.
**SIGNS OF IMMINENT DEATH**
- reduced social interaction, sleeps more, acts confused or disoriented, coma
- decreased intake of food and drink - no hunger or thirst
- reduced urine and bowel movements, maybe incontinent
  - slow irregular breathing ‘death rattle’
  - skin changes, cold and greyish looking fingers, feet

**SIGNS OF DEATH**
- breathing stops completely
- heart beat and pulse stops
- totally unresponsive to calling or shaking
- eyes fixed in one direction, pupils dilated
- change in skin tone, maybe blotchy

**HELPING WHEN THE SICK PERSON FINISHES UP/DIES**

The time of finishing up/death can be experienced differently for every family and person.

A number of factors impact of peoples reaction to finishing up/death:
- cultural norms
- beliefs of family and the community
- if people have experienced finishing up/death before
- if experiences have been positive or negative
- the gravity of the loss - child or parent
- were people prepared or was it a shock.

Sometimes, in the last half hour the sick person may become restless and agitated, they may open their bowels and urinate. Some medication to settle the agitation may be given, this will also help with the sick persons level of comfort. It is important that the sick person is changed into clean clothing and that the bedding be changed. The agitation may be upsetting for some family members to watch. It is important that they know that the sick person is preparing to finish their journey.
Everyone will react differently when the sick person finishes up/dies. Some family members may:

• talk to the sick person throughout the journey
• call the spirit home by singing and or dancing
• wail or cry loudly,
  » this is a normal reaction to grief and loss and should not be discouraged
  » if other persons are concerned for loud noises recognise the loss that has occurred
• go quiet not wanting to talk
• get angry and blame someone for the loss
• want to stay near the deceased
• commence preparations for the body & the spirits transition
• use comfort measures like prayers.

Generally, palliative care providers will ensure the family are the ones with the sick person when they finish up. Some family may want to stay with the loved one. Remember this may be dependent on the kinship relationship.

As the sick person finishes up, the sense of loss and grief immediately confronts most. Although this is a time of sadness, some family members have ongoing care responsibilities.

If at home, in the community, the treating doctor or palliative care service needs to be advised of the finishing up/death as soon as possible. This should be the first phone call made. Often this does not happen between 9-5, contact can be made to advise of finishing up at anytime. The doctor will visit the sick person and family to confirm the finishing up/death so a death certificate can be issued.

While grief and loss needs time, do check with those present how they are going considering the recent events. After that it may be time for the family to grieve and have some space from care providers. Give your condolences and let them know when you will come back to visit. Don’t leave that visit too long. Care providers may have been visiting for some weeks or months and when that stops, that can feel like another loss to some family members.
What have you found helpful and what was unhelpful when you are dealing with sad news and sorry business?
4.8 LEGAL REQUIREMENTS WHEN DEATH OCCURS

When someone finishes up/dies at home or a hospital, the first step is to notify the treating doctor or specialist palliative care team that has been supporting the sick person and family. The doctor, palliative care service or hospital authorities will explain the steps for the death certificate to be completed, some personal family information is required for this legal document.

A doctor will clarify medically that finishing up/death has occurred and the case of finishing up/death is acknowledged with a signed document known as the Doctor’s Certificate of Cause of Death or Death Certificate. The doctor will advise of a signed certificate, at this time the funeral director can be contacted to collect the deceased. While arrangements can be planned, the funeral cannot be conducted until a death certificate has been issued.

If the cause of death is unknown to the doctor, the coroner must be contacted along with the police. The requirement is for an autopsy to clarify cause of death and then a death certificate will be issued. Police will arrange for the deceased to be transported to the forensic morgue. This process may take an extended time.

The finishing up/death will also need to be registered, as the funeral director generally collects the relevant information, it is collated and sent to the relevant state or territory government office. The funeral director may also provide the family with the death certificate.

If the families are unsure of a funeral home, the Funeral Directors Association in your state or territory can help.

If a funeral director is not involved with the funeral arrangements, the person who manages the final arrangements for the deceased is responsible for registering the death.
ACTIVITY

Describe what is happening to prepare for Pop-Arthur’s family funeral. (See page 16 and 17 of the comic book).
How does reminiscing about the deceased person’s life help the family in their grieving?

How can you help other health care providers to understand the family’s needs when their loved one dies?
SUPPORT FOR FAMILIES AFTER SOMEONE HAS FINISHED UP/ DIED

Help family to contact social services to find out about ways the department can support the family and help with financial allowance if this is needed.

Table 6: Information from the Commonwealth Department of Human Services

<table>
<thead>
<tr>
<th>The following practical information for bereaved family is available from internet site of the Australian Government Department of Human Services at; <a href="http://www.humanservices.gov.au/customer/subjects/what-to-do-following-a-death">http://www.humanservices.gov.au/customer/subjects/what-to-do-following-a-death</a></th>
</tr>
</thead>
</table>

Grieving

Grieving is a natural reaction when losing someone close to you, so adjusting to your new circumstances may take time. Counsellors can often assist people who are grieving. A social worker can refer you to grief counselling. Counsellors can also be contacted through organisations such as community health centres, the National Association for Loss and Grief or Lifeline.

Loneliness

It may seem difficult at first to take part in social groups and activities. You may or may not want people around you. With time, the company of others may help you develop new interests. Your local council, community health centre or our social workers can put you in touch with organisations such as Rotary or Apex that would value your assistance as a volunteer. You can also join in their activities and outings.

Health

Taking care with your diet and regular exercise can assist you re-establish a routine. We can arrange for visits by a community nurse if necessary. Community groups or local councils may arrange services to help care for your house or garden. Some of these services are free and some may be provided only after your needs have been assessed.

Housing

You may want to stay in your family home. However, if this is difficult, think about all the options carefully before you decide on a change. Moving too quickly may not be the best solution.

You can talk to one of our Financial Information Services Officers who can give you information about how any decisions you make could affect the payment you receive from us.

CONCLUSION

Congratulations you have completed module 4.

In this module we identified some expected physical and emotional problems and spiritual concerns of people with advanced or end-stage illness. We considered communication guidelines for gathering information about the sick person’s concerns and needs. We also explored the principles of assessing a person’s pain using appropriate questions and pain measurement scales. The treatment of pain identified included medication and non-medical interventions such as providing emotional, cultural and spiritual support and physical care. Also in this module, we identified other common symptoms, their treatment and practical interventions that can help you in supporting families in their carer role. The module concluded by examining the process when a sick person nears the end and we identified practical points for helping the family during and after the person’s finishing up/death.

Well Done!
BIBLIOGRAPHY


Palliative Care Curriculum for Undergraduates (PCC4U) Project Team (2012) Implementation Guide: Student learning resources. Brisbane QUT.

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

**SECTION 1- A WORKPLACE PLACEMENT**

**1.1 APPLYING FOR A WORKPLACE PLACEMENT**

Application forms are available on the PEPA website. Directions are below:

1. go to [http://www.pepaeducation.com](http://www.pepaeducation.com) you will land on the home page
2. go to the bottom of the page (the sitemap). The second row is named APPLY, underneath it is a list of states and territories. Click on your state or territory
3. you will be taken to your state’s PEPA website to Application forms, information guides and workshop dates. Go to application forms and print the application form
4. complete the relevant details (Section A, B, C, D, G, H, I & K and others as indicated)
5. give the application to your Manager. They will need to fill out a section to support your application
6. return the completed application form to your PEPA Manager.

*If you have any questions or concerns, please contact your PEPA Manager or Aboriginal Project Officer.*

They will assist you

REMEMBER: always make a copy of your finalised application for your reference.

**1.2 CONFIRMING YOUR PLACEMENT ACCEPTANCE**

Shortly after receiving your Application Form or your Registered Interest Form, your PEPA Manager will contact you to talk about your placement application.

If you have not participated in a PEPA workshop, they will also discuss your access to the PEPA online learning program. This can be accessed at any time, although you will need a user ID and password. The PEPA Manager will provide them to you in a timely manner.

You will receive written confirmation about your placement and the Specialist Palliative Care Service (Hospital or Community). Attach (using staples) the confirmation to this Learning Guide. So that you can gain the most from your workplace placement, an experienced palliative care Mentor will assist you. They may work at the Site where you will undertake your placement or it may be the PEPA Aboriginal Project Officer.

It is time to think about your Pre-placement Learning Plan and your previous work experiences. It is good to talk to your Mentor about these things, to make sure your placement meets your expectations and needs. There is a form at the end of this section to summarise this information. All forms to be returned are in Appendix 2.
1.3 PEPA CONTACTS AND HOST SITE CONTACTS

PEPA has a team in each state and territory. If you have any queries or concerns about your placement application or registering your interest to attend a placement, please contact the PEPA Manager in your State or Territory. He/she will be able to direct you to the relevant information/person to address your queries.

PEPA MANAGER DETAILS

If there is no contact details here, you will find all the details you need on the website.

PEPA ABORIGINAL PROJECT OFFICER DETAILS

The PEPA Aboriginal Project Officer may also be a valuable resource for you.

Visit the website for the contact details of the PEPA team in your State or Territory.

Website http://www.pepaeducation.com
HOST SITE CONTACTS

Once your placement has been confirmed, your host contact person and/or mentor will be your main contact regarding information relating to your Host Site and placement activities.

Host Site 1

Host Contact person: ____________________________________________________________

Host Mentor: _________________________________________________________________

Address: _________________________________________________________________

Phone: _________________________________________________________________

Email: _________________________________________________________________

Host Site 2

(If applicable)

Host Contact person: ____________________________________________________________

Host Mentor: _________________________________________________________________

Address: _________________________________________________________________

Phone: _________________________________________________________________

Email: _________________________________________________________________

Host Site 3

(If applicable)

Host Contact person: ____________________________________________________________

Host Mentor: _________________________________________________________________

Address: _________________________________________________________________

Phone: _________________________________________________________________

Email: _________________________________________________________________
1.4 PRIOR TO YOUR PLACEMENT -
LOOK OVER THE WORKSHOP MODULES TO REFRESH

It is important to refresh your learnings from the workshop prior to attending your placement. This will prepare you on how the principles you have learnt can be applied in your practice of the palliative approach.

**ACTION:** Have a look at your completed Workshop in the beginning of this guide. Refresh your memory of the activities and your responses.

**QUICK REVIEW**
Become familiar with the definition of palliative approach to care and the more specific person centred activities that support Quality of Life (QoL), the providers of palliative care and the needs of people with life limiting illness.
SECTION 2- PREPARING FOR YOUR PLACEMENT

In this section, the roles and responsibilities of participants, the host site, your mentor and the PEPA state/territory Manager are outlined. Please read these carefully so that you have a clear understanding of expectations for each person and host site involved.

2.1 WHO’S WHO AND ROLES AND RESPONSIBILITIES

Responsibilities of the workplace placement Participant

• be familiar with the workshop content and work through the placement activities in this learning guide
• prepare for the supervised placement by referring to the educational resources provided and identifying your individual learning needs for your experiential placement
• actively participate in the supervised placement (within the scope of your discipline, skills and experience while under supervision), and consider how learning can be transferred into your own working environment
• be sensitive to the work demands of the mentor
• abide by the policies and procedures of the host site
• reflect on your experience and critically appraise care provision of people in your community
• undertake an activity on return to your own workplace/practice within three months of completing the supervised clinical placement to promote transfer of your learning
• complete and return all evaluation documents
• complete, copy and forward record of placement to the PEPA Manager for documenting continuing professional development hours
• notify the PEPA Manager and comply with the host site policy, in the event that any injury or illness occurs on placement
• notify the Mentor and PEPA Manager if you are unable to attend your supervised clinical placement for any reason.

BE MINDFUL

• be aware that your placement is in a specialist palliative care service, the nature of this service is that it is a respectful place to finish up/die
• your placement may be in a specialist palliative care service that you and neighbouring communities refer to throughout the end of life care pathway
• it is probable that someone will finish up/die on while you are doing your placement
• it is possible that someone you know may be utilising the service where you are doing your placement
• it’s important to remember that confidentiality is maintained and that any potential conflict of interest is declared to your mentor or host site staff
• if necessary, your mentor or the host site staff will follow this up with the known person.

Responsibilities of the PEPA Manager
• be familiar with the contents of the PEPA Communications and Mentoring Guides
• coordinate and implement the PEPA program experiential placements and supportive activities
• resolve any procedural issues that may arise during the course of the experiential placement and supportive activities
• ensure the participant is placed in a suitable host facility to meet their learning needs

Responsibilities of the Host Site
• provide mentors who have appropriate clinical teaching experience
• be familiar with the contents of the PEPA Mentoring Guide
• be familiar with the PEPA Communications Guide
• ensure that mentors are aware of the dates that they have been assigned a participant
• ensure that the participant is supernumerary to the staffing of the service
• ensure that the participant is aware of local policies and procedures relating to safety and security
• complete and return the evaluation survey every six months
• advise the PEPA manager of any issues or concerns during the supervised clinical placement

Responsibilities of the Mentor
• be familiar with the contents of the PEPA Mentoring Guide
• be familiar with the PEPA Communications Guide
• be familiar with the contents of the PEPA Participant Learning Guide relevant to your discipline (online versions of all guides are available for download from the PEPA website) http://www.pepaeducation.com
• plan time and working arrangements for the placement period
• incorporate the features of a ‘best practice’ PEPA placement as outlined in the Mentor Guide
• sign off on the participant’s supervised clinical placement documentation as appropriate for allocation of Continuing Professional Development hours.
2.2 PROCESS FOR RESOLVING ISSUES

While every effort will be made to ensure appropriate placements, at times a participant or host site might identify a problem with the placement. The mentor, participant and host venue need to address the issue and, if this does not work, the mentor can contact the PEPA Manager in their State or Territory to resolve the problem (http://www.pepaeducation.com).

We suggest that you follow the simple process below to help you ascertain the extent of the issue and take appropriate action:

• in the first instance, clarify in your own mind what the issue seems to be from your point of view. Then see if you can think about the issue from the other person’s point of view. Taking both perspectives into account, think of possible solutions or alternative ways you might move the situation forward
• introduce the topic of concern in your next meeting, or if appropriate before your next meeting. Outline your concerns and ask the other person how they perceive the issue. Use the information from both points of view to find a way of working through the issue to an appropriate solution
• if an appropriate solution cannot be agreed upon, either party may contact the PEPA Manager to resolve the problem.

Where a serious issue or concern arises, follow the appropriate policies and procedures for your host site service and inform the PEPA Manager as soon as practicable.
2.3 PARTICIPANT BACKGROUND KNOWLEDGE & EXPERIENCE

NOTE: COPIES OF DOCUMENTS TO BE RETURNED ARE IN APPENDIX 2
(complete and forward to your mentor with your pre-placement learning plan)

It will be helpful for your mentor and host site to understand your background knowledge and experience, as well as what you hope to learn from your PEPA placement. Fill in this page and return to your PEPA manager who will forward it on to your host site so that they know how to better assist you during your placement.

What is your background in terms of professional experience and qualifications?

What previous experience and/or education have you had in palliative care?

When completing your PEPA application, you completed questions to assist in developing an awareness of what your palliative learning goals were and what you would like to take away from your Placement.

Attach a copy of the Goals and Objectives from your application here.
YOUR PRE-PLACEMENT LEARNING PLAN

Think about your learning needs and goals and how you will be able to meet these. Think about which people at the Host site will be able to help you achieve your goals and how they might be able to do this. Remember, you only have a few of days at the host site so you will need to plan to maximise your learning.

Below are some activities of palliative care facilities. These may be helpful with your pre placement learning needs and plan. Circle activities you would like to experience in the end of life (EoL) care path and discuss with your Mentor.

What would you like to see or experience during your placement?

<table>
<thead>
<tr>
<th>Ward Rounds</th>
<th>Handover</th>
<th>Case Conferencing</th>
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<tbody>
<tr>
<td>Team meetings</td>
<td>Family meetings</td>
<td>MDT meeting</td>
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<tr>
<td>Training or Inservice</td>
<td>Assessments</td>
<td>ACP / Bereavement</td>
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<tr>
<td>Roles of diverse disciplines</td>
<td>Different EOL stages</td>
<td>Personal Cares</td>
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<tr>
<td>Discussions addressing troubling symptoms/ difficult conversations</td>
<td></td>
<td></td>
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<tr>
<td>Visit service settings - hospital, community, specialist service, admissions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Body cares after finishing up/death (washing and laying out)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other: ..................................................................................................................................................................................

Is there anything that may be inappropriate for you to participate in?

..................................................................................................................................................................................

..................................................................................................................................................................................

Is there anything you are unsure or uncomfortable about?

..................................................................................................................................................................................

..................................................................................................................................................................................

Name ..................................................................................................................................................................................

Signature ..........................................................................................................................................................................

Date ..................................................................................................................................................................................
2.4 Suggested Pre-reading and Activities

In this workbook, at the end of the placement Sections are ‘Palliative Care Resources”.
Source and read through a variety of articles, websites and videos. Your PEPA Manager will be able to assist you to access some of these resources.

Access to some documents and resources may change over time. To ensure your access is ongoing, two websites that have comprehensive information with access to Palliative Care and Aboriginal and Torres Strait Islander Palliative Care and related matters are listed below.

**CareSearch**
The palliative care knowledge network that provides online resources of palliative care information and evidence for relevant readings. The Clinical Practice link has valuable information surrounding physical symptoms, psychological, social and spiritual issues, patient considerations, diseases and conditions and information pertaining to families, carers, and professional and specific population groups.

http://www.caresearch.com.au

**Australian Indigenous HealthInfoNet**
Aboriginal and Torres Strait Islander HealthInfoNet is a comprehensive health and wellbeing website for everybody. Edith Cowan University, Western Australia.

The site addresses information about of health concerns for Aboriginal and Torres Strait Islander people, policies and reports for specific health matters, projects and resources for health care providers and community, online yarning groups for concerning matters, statistical population data and Closing the Gap initiatives.

http://www.healthinfonet.ecu.edu.au
SECTION 3- UNDERTAKING YOUR PLACEMENT

During your PEPA placement you will have the opportunity to see core skills in practice. These core skills enable you to provide a palliative approach to care. They include skills in communication, symptom management, providing psychological, spiritual and cultural support. These core skills are utilised by health care providers providing a palliative approach to care.

You will need to refresh your memory about communication with people who have life limiting illness - ‘PREPARED’ (pages 15-16)

THE FOLLOWING ACTIVITIES ARE FOR YOU TO COMPLETE DURING YOUR PLACEMENT

3.1 COMMUNICATION WITH PEOPLE WHO HAVE A LIFE LIMITING ILLNESS

ACTIVITY

1. What specific communication strategies did you observe that health care providers used in the following situations? You may also wish to discuss your responses to this question with your mentor.

Responding to a sick persons’ emotional distress

Introducing the concept of palliative care
Responding to queries about dying

ACTIVITY

2. Make a list of communication strategies you will use in the future to support individuals with a life limiting illness and their families.
3.2 ASSESSMENT PROCESSES IN PALLIATIVE CARE

Assessment is an essential process to ensure that the person with a life limiting illness and their family’s beliefs, needs and choices are known and that appropriate intervention or treatment is provided. It is important to apply a holistic approach that means considering all domains of the person’s life when assessing their symptoms.

The five domains making up the circle of palliative care are shown in diagram 1.

**The Five Domains of Holistic Care***

![Diagram of the Five Domains of Holistic Care](image-url)

*Adapted from PEPA Project Team (2010), The Program of Experience in the Palliative Approach Aboriginal and Torres Strait Island Health Workers’ Learning Guide. Brisbane, Queensland University of Technology.*
ACTIVITY

During your placement, observe the assessment methods and how the observations are recorded in the palliative care service that you visit. You may find the following guidelines useful:

- listen to the sick person and their family’s story about the illness and symptoms
- look for contributing factors or situations that make the symptoms or distress worse, for example: movement, position, emotions, anxiety, fear
- ask about the impacts or outcomes of the sick person’s treatment, medications and other therapies they are using
- observe the sick person for signs and symptoms of changes in their physical condition
- ask the sick person “what is worrying them the most?”
- talk to the primary carer(s) about changes, symptoms or moods they have noticed
- check for other changes in the sick person’s spiritual, emotional, cultural, social and family needs.
3.3 Common Symptoms Associated with Advanced or Chronic Illness

People with advanced disease or chronic illness can have physical, psychological (emotional), cultural and spiritual symptoms.

During the workshop, you looked at some common symptoms and treatments (pages 61-62). The following table will progress your workshop learning.

During your placement, you will have the opportunity to observe and discuss strategies for managing these concerns. Please ensure that you stay within your scope of practice.

**ACTIVITY**

Refer to the CareSearch website at http://www.caresearch.com.au and read the section on Physical Symptoms under Clinical Practice. As pain is a common symptom experienced by those facing life limiting illness and can be difficult to control due to its complex nature, it will be beneficial for you to pay particular attention to the Pain section and to do further readings.

The following table lists physical symptoms that are common in advanced disease and chronic illness. During your PEPA Clinical Placement, write down what you learn about these symptoms and how they are treated in palliative care.

<table>
<thead>
<tr>
<th>SYMPTOM or INDICATOR</th>
<th>PALLIATIVE TREATMENT/ MANAGEMENT TECHNIQUES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Pain</td>
<td></td>
</tr>
<tr>
<td>• Neuropathic (nerve &amp; tissue pain)</td>
<td></td>
</tr>
<tr>
<td>• Nociceptive (skin, muscle &amp; organ pain)</td>
<td></td>
</tr>
<tr>
<td>• breakthrough pain (after taking pain relief, the pain returns or worsens hours before next dosage is due)</td>
<td></td>
</tr>
</tbody>
</table>
## Symptom or Indicator

### Gastric problems

- vomiting *(spu)*
- nausea
- constipation *(blocked up)*
- diarrhoea *(runny belly)*
- incontinence - bladder

### Breathing difficulties

- breathlessness
- coughing - dry or moist cough

### Reduced energy level
## Symptom or Indicator

<table>
<thead>
<tr>
<th>Symptom or Indicator</th>
<th>Palliative Treatment/Management Techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Loss of appetite</strong></td>
<td></td>
</tr>
<tr>
<td>• Cachexia (excessive physical wasting)</td>
<td></td>
</tr>
<tr>
<td>• Anorexia (lack of appetite)</td>
<td></td>
</tr>
<tr>
<td>• Dehydration (excessive water and salt loss)</td>
<td></td>
</tr>
<tr>
<td>• Difficulty swallowing / dysphagia</td>
<td></td>
</tr>
<tr>
<td>• Dry mouth</td>
<td></td>
</tr>
<tr>
<td>• Oral complications/ infections</td>
<td></td>
</tr>
<tr>
<td><strong>Skin problems</strong></td>
<td></td>
</tr>
<tr>
<td>• Itching</td>
<td></td>
</tr>
<tr>
<td>• dryness</td>
<td></td>
</tr>
<tr>
<td>• Malignant wounds (open skin ulcers)</td>
<td></td>
</tr>
<tr>
<td><strong>Oedema (swelling)</strong></td>
<td></td>
</tr>
<tr>
<td>SYMPTOM or INDICATOR</td>
<td>PALLIATIVE TREATMENT / MANAGEMENT TECHNIQUES</td>
</tr>
<tr>
<td>----------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Confusion delirium restlessness</td>
<td>NOTE: this may conflict with cultural beliefs OR mixed with nausea and vomiting may allude to the strength of a medication</td>
</tr>
<tr>
<td>Infections (bacterial, viral)</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
</tr>
<tr>
<td>Insomnia- (lack of sleep)</td>
<td></td>
</tr>
<tr>
<td>Fatigue (extreme lack of energy)</td>
<td></td>
</tr>
<tr>
<td>Nightmares</td>
<td></td>
</tr>
<tr>
<td>Others symptoms</td>
<td></td>
</tr>
</tbody>
</table>
3.4 END OF LIFE CARE

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

All illnesses have known trajectories, awareness of symptoms or changes that indicate advancing stages and milestones throughout the end of life care path. Every sick person and their family members should be empowered throughout the end of life care path with open communication about the illness progression, allowing awareness of milestones before they occur.

It is important for you to be able to recognise the end of life symptoms so you can continue to explain the progression of the path with the final milestones.

While this does not reduce the sense of loss, it does however provide empowering awareness to family members which allows the opportunity for precious last moments with the sick person. This is recognised as a positive supportive and awareness tool for family members ensuring that the final milestones are expected and health care providers are respected.

Identifying the journey’s path sensitively and clearly enables each person’s responsibility and enables the path for healthy grieving and bereavement for the loss, while leaving no room for matters of blaming around the palliative approach in the end of life care path. This also provides a positive experience of interactions with health care providers and services around finishing up/death.

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 patchy
- loss of appetite, any offer of food may be refused
- 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,
- longer periods of semi-consciousness with laps of unconsciousness

(Australian Palliative Residential Aged Care project team 2006)
ACTIVITY
Talk with your mentor 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 down what you learn about end-of-life care.
3.5 LOSS, GRIEF AND BEREAVEMENT

Loss, grief and bereavement are normal experiences of life. The pain of loss, grief and bereavement can be experienced physically, emotionally, culturally and spiritually and the consequences can affect social and family relationships. Everyone experiences loss and grief and responds in their own way, people in the same family may react differently. Understanding these responses will help you to support the sick person and family members while helping them understand that people react differently to the same situation.

**ACTIVITY**

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

*Write down the losses a person with a life limiting illness may experience.*
The way people cope with loss can be influenced by many factors like their cultural, spiritual and religious beliefs and practices, learnt behaviours from family and influential others, along with personal perspectives about loses and coping mechanisms.

Some people have dealt with several devastating losses during their life, for example, the loss of a child, or loss of loved ones through accidents or violence, or loss of the family home through bush fires, or loss of identity family and culture through policy and others have had very few losses in their lifetime.

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.

The following are some responses experienced by people who are grieving:

- **Mental** confusion, preoccupation, hallucinations, dreams of the deceased person
- **Emotional** numbness, 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, dull constant headache
- **Behavioural** overactivity, 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
- **Cultural** extreme sorrow, wailing (loud crying), singing, self harm by cutting or hitting (this can be linked to a mourning period), period of mourning, connectedness, carrying treasure of decease, sorry camps/business responsibilities.

**PLEASE NOTE:** There may be many other responses that are not listed above

Bereavement is the period of grieving experienced by family and friends after a loved one has finished up/died. 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 care provider, or volunteer trained for this type of work. Some palliative care organisations have an annual memorial service for the families of people who have finished up/died.
ACTIVITY

Talk with your mentor or another palliative care specialist about how loss, grief and bereavement reactions are supported in your placement setting.

ACTIVITY

What strategies can you implement when you return to your own practice settings to support individuals experiencing loss, grief and bereavement?
ACTIVITY

Look into the services and resources for individuals and families dealing with loss, grief and bereavement in your local area.
3.6 SELF CARE

It is normal for you in your role as a health care provider to become attached to the people you care for. So you can experience some of the symptoms of grief when witnessing a decline in the health of the people you are caring for. It is important for your health that you acknowledge your grief and find time to share feelings and thoughts with other colleagues, friends or family members.

**ACTIVITY**

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

**ACTIVITY**

During your PEPA workplace placement ask about the different ways that carers are supported in their grief.
SECTION 4 - COMPLETION OF YOUR PLACEMENT

In this section, we will review your original goals and objectives, reflect on what you have learnt during your placement, and examine strategies you can use to implement your learning in your workplace.

A Placement Completion Form to return to your states PEPA Manager (forms to be returned are in Appendix 2)

4.1 DEVELOPING SUPPORTIVE NETWORKS

In the workshop we completed a local palliative care team (pages 39-41). If your placement site is a distant service, it may be practical to get details of this team for ongoing interaction of advice and support.

The first step towards developing networks with palliative care specialist providers is getting to know the palliative care specialists that support your local services. 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 workplace.

<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 Practitioner (GP)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OCCUPATION</td>
<td>NAME</td>
<td>CONTACT DETAILS</td>
</tr>
<tr>
<td>----------------------------</td>
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<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 Health Worker</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>
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<tr>
<td>Occupational Therapist</td>
<td></td>
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<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>
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<tr>
<td>Local Pharmacists</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### SECTION 4 - COMPLETION OF YOUR PLACEMENT

<table>
<thead>
<tr>
<th>OCCUPATION</th>
<th>NAME</th>
<th>CONTACT DETAILS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volunteers in Community</td>
<td></td>
<td></td>
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<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>
4.2 Placement Completion Form
(Return a copy to your PEPA Manager with 14 days)

Participant’s name: _____________________________________________________________
AHPRA number: _______________________________________________________________
Name of own workplace: _______________________________________________________
Postal Address: ________________________________________________________________
Phone: _______________________________________________________________________
Email: _______________________________________________________________________

<table>
<thead>
<tr>
<th>Number of Hours Completed at site</th>
<th>Signature</th>
<th>Print name</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your PEPA manager</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Host Facility 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name and Address</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your mentor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Host Facility 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name and Address (if applicable)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your mentor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Host Facility 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name and Address (if applicable)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your mentor</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
4.3 REFLECTION OF LEARNING

Now you have time to reflect, go back to Section 2 and review each of your goals in your learning plan.

**Have you met your initial goals? If they have changed, what may have influenced this?**

List the key areas of learning and new skills you have acquired during your workplace placement.
Which of this new knowledge and new skills will you be able to take back to your own workplace?

Think about the resources and other members of your workplace will help you to integrate what you have learnt at your workplace.
4.4 POST PLACEMENT WORKPLACE ACTIVITY PLAN AND REFLECTION

Now that you are back in your workplace, make a plan for a palliative care project and implement it. It can take any form you think is applicable to your workplace. Here are some ideas:

- organise a workshop or present an in-service or case study
- design an assessment tool for your workplace
- develop a palliative care resource folder
- amend or introduce a policy and procedure
- conduct a research activity
- plan something for the annual Palliative Care Week

When devising your post placement activity, consider aspects such as:

- approximately how many people will you expect to attend?
- where will you hold the activity?
- what resources will you require?
- how might this positively affect the people that attend the workshop?
- what knowledge do you expect the workplace/participant to gain in relation to palliative care?
- how will you evaluate workplace/participant’s knowledge pre and post activity?

Once you have decided what to do, discuss your ideas with the manager in your workplace and make the necessary arrangements to undertake the activity. Briefly, describe your activity in the space below, considering some of the aspects above.

WORKPLACE ACTIVITY PLAN

Outline the activity you will undertake

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
How will the activity influence the care of a person with a life-limiting illness in your or your colleagues' care?

Where will the activity be conducted and who will be involved?

How will you evaluate the activity?

Date of implementation: ________________________________
Participant's signature: ________________________________
Date: ________________________________
Workplace Manager's signature: ________________________________
Date: ________________________________
4.5 POST WORKPLACE ACTIVITY REFLECTION

At three months post placement, you will be asked to complete a questionnaire about your PEPA experience, by your PEPA state manager. This is an important part of your learning experience and for the evaluation of the PEPA project. The evaluation will ask you to consider:

What knowledge and skills have you gained from your PEPA placement?
How have your own practices changed in the palliative approach?
What changes have occurred at your workplace since your placement?
In what way did your Post Placement activity influence your workplace practices?
INTERNATIONAL
Worldwide Palliative Care Alliance (2014), *Global Atlas of Palliative Care at the End of Life*, World Health Organisation (annual issue)

AUSTRALIA’S POLICY DOCUMENTS
http://www.health.gov.au/Home/For Consumers>Palliative Care
The Australian Government National Health and Medical Research Council, (2011) *An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions.*

REPORTS
Australian Institute of Health and Welfare, *Palliative Care in Australia 2012* Cat no. HWI 120. Canberra: AIHW
Australian Institute of Health and Welfare (AIHW) and Cancer Australia, (2013) *Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview*

DICTIONARIES
Palliative Care Curriculum for Undergraduates (PCC4U), *Glossary* http://www.pcc4u.org
**CLINICAL PRACTICE GUIDELINES**


Learning Guide for Aboriginal and Torres Strait Islander Health Workers080414.docx


Learning Guide for Aboriginal and Torres Strait Islander Health Workers080414.docx

Pain Australia, National Pain Strategy (2011) *Pain Management for all Australians*

**SERVICE DELIVERY**


Numerous state and territory projects were funded (2005–2006,2011). 
http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=455

Koori Human Services Unit (2008), *Improving care for Aboriginal and Torres Strait Islander patients (ICAP) Resource Kit*, Victorian Department of Human Services. 
http://www.healthinfonet.edu.au/key-resources/promotion-resources?lid=15917

Aboriginal and Torres Strait Islander Health Branch (2011), *Sad news, sorry business: guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying*. Queensland Health. 


Respecting patient Choices Team Telephone: (03) 9496 5000

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**RESOURCES**
RESEARCH FINDINGS


COMMUNICATION

PEPA Project Team (2010) Communication Guidelines for engaging Aboriginal and Torres Strait Islander Health Professionals, Queensland University of Technology, Brisbane.
http://pepaeducation.qut.edu.au

PEPA Project Team (2010) Guidelines for Mentoring Aboriginal and Torres Strait Islander Health Professionals, Queensland University of Technology, Brisbane.
http://pepaeducation.qut.edu.au


Australian Psychology Society ‘Changing Practice, Changing paradigms’ http://www.psychology.org.au

John Cunningham (revised 2008). Compassionate Communication and Empathy’s Awakening

PEPA Project team (2014) Cultural Considerations Providing End of Life Care for Aboriginal people and Torres Strait Islander people.
http://www.pepaeducation.com
GRIEF AND BEREAVEMENT

Centre for Grief & Loss, Dubbo ( ). *Finding a path to healing, ongoing collaboration to build resilience in an overburdened community*
Creative Spirits *Mourning Aboriginal Death* http://www.creativespirits.info

SELF-CARE AND SUPERVISION RESOURCES

End of life / Palliative Education Resource Centre (EPERC), *Fast Facts Documents #167 - #170 Health Professional Burnout*.

SPIRITUAL CARE

AGED CARE POLICY


PAEDIATRIC PALLIATIVE CARE


GENERAL RESOURCES


JOURNALS
Grief Matters: Australian Journal of Grief and Bereavement
Aboriginal and Islander Health Worker Journal
Journal of Palliative medicine
Journal of Pain and Symptom Management
Journal of Pain
Palliative Care Journal
Progress in Palliative care
Mortality Journal
Palliative and Supportive Care (http://www.journals.cambridge.org)
Palliative Supportive Care (Cambridge University Press, United Kingdom)
International Electronic Journal of Rural and Remote Health Research,
   Education Practice and Policy
American Journal of Hospice and Palliative Medicine
Australian Journal of Holistic Nursing
Australian Journal of Primary Health
Austral-Asian Journal of Cancer

WEBSITES - Bereavement

<table>
<thead>
<tr>
<th>Australian Centre for Grief and Bereavement</th>
<th><a href="http://www.grief.org.au">http://www.grief.org.au</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal Counselling Service</td>
<td><a href="http://www.AboriginalCounsellingServices.com.au">http://www.AboriginalCounsellingServices.com.au</a></td>
</tr>
<tr>
<td>Grief Speaks</td>
<td><a href="http://www.griefspeaks.com">http://www.griefspeaks.com</a></td>
</tr>
<tr>
<td>Grief Link</td>
<td><a href="http://www.grieflink.com">http://www.grieflink.com</a> <a href="http://www.grieflink.asn.au">http://www.grieflink.asn.au</a></td>
</tr>
<tr>
<td>WEBSITES- Educational/research</td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Caresearch</strong></td>
<td></td>
</tr>
<tr>
<td>Palliative Care Knowledge Network</td>
<td><a href="http://www.caresearch.com.au">http://www.caresearch.com.au</a></td>
</tr>
<tr>
<td><strong>Palliative Care Curriculum for Undergraduates PCC4U</strong></td>
<td><a href="http://www.pcc4u.org">http://www.pcc4u.org</a></td>
</tr>
<tr>
<td><strong>PEPA</strong></td>
<td></td>
</tr>
<tr>
<td><a href="http://www.pepaeducation.com">http://www.pepaeducation.com</a></td>
<td></td>
</tr>
<tr>
<td><strong>Palliative Approach to Community Aged Care Online course</strong></td>
<td><a href="http://www.palliativecareonline.com">http://www.palliativecareonline.com</a></td>
</tr>
<tr>
<td><strong>EdCaN - the national cancer nursing education project</strong></td>
<td><a href="http://www.edcan.org.au">http://www.edcan.org.au</a></td>
</tr>
<tr>
<td><strong>Australian Resource Centre for healthcare Innovations (ARCHI)</strong></td>
<td><a href="http://www.archi.net.au">http://www.archi.net.au</a></td>
</tr>
<tr>
<td><strong>The Benevolent Society</strong></td>
<td><a href="http://www.benevolent.org.au">http://www.benevolent.org.au</a></td>
</tr>
<tr>
<td><strong>Centre for Palliative Care</strong></td>
<td><a href="http://www.centreforpallcare.org">http://www.centreforpallcare.org</a></td>
</tr>
<tr>
<td><strong>Centre for Palliative Care Research and Education, Queensland Health</strong></td>
<td><a href="http://www.health.qld.gov.au/cpcre/">http://www.health.qld.gov.au/cpcre/</a></td>
</tr>
<tr>
<td><strong>Centre Cultural Competence Australia</strong></td>
<td><a href="http://www.cccq.com.au">http://www.cccq.com.au</a></td>
</tr>
<tr>
<td><strong>Creative Spirits</strong></td>
<td><a href="http://www.creativespirits.info">http://www.creativespirits.info</a></td>
</tr>
<tr>
<td><strong>Australian Indigenous HealthInfoNet</strong></td>
<td><a href="http://www.healthinfonet.ecu.edu.au/">http://www.healthinfonet.ecu.edu.au/</a></td>
</tr>
</tbody>
</table>
## WEBSITES - Educational/research

<table>
<thead>
<tr>
<th>Website</th>
<th>URL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reconciliation Australia</td>
<td><a href="http://www.australia.gov.au">http://www.australia.gov.au</a></td>
</tr>
<tr>
<td>Reconciliation Qld</td>
<td><a href="http://www.rqi.org.au">http://www.rqi.org.au</a></td>
</tr>
<tr>
<td>Reconciliation NSW</td>
<td><a href="http://www.nswreconciliation.org.au">http://www.nswreconciliation.org.au</a></td>
</tr>
<tr>
<td>Reconciliation SA</td>
<td><a href="http://www.reconciliationsa.org.au">http://www.reconciliationsa.org.au</a></td>
</tr>
<tr>
<td>Reconciliation WA</td>
<td><a href="http://www.reconciliationwa.org.au">http://www.reconciliationwa.org.au</a></td>
</tr>
<tr>
<td>Reconciliation VIC</td>
<td><a href="http://www.reconciliationvic.org.au">http://www.reconciliationvic.org.au</a></td>
</tr>
</tbody>
</table>

## WEBSITES - Lead Agencies

<table>
<thead>
<tr>
<th>Organization</th>
<th>URL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal and Islander Doctors Association</td>
<td><a href="http://www.aida.org.au">http://www.aida.org.au</a></td>
</tr>
<tr>
<td>Council of Aboriginal and Torres Strait Islander Nurses and Midwives</td>
<td><a href="http://www.catsin.org.au">http://www.catsin.org.au</a></td>
</tr>
<tr>
<td>National Aboriginal and Torres Strait Islander Health Worker Association</td>
<td><a href="http://www.natsihwa.org.au">http://www.natsihwa.org.au</a></td>
</tr>
<tr>
<td>NACCHO National Aboriginal Community Controlled Health Organisations</td>
<td><a href="http://www.naccho.org.au">http://www.naccho.org.au</a></td>
</tr>
<tr>
<td>QLD</td>
<td><a href="http://www.qaihc.com.au">http://www.qaihc.com.au</a></td>
</tr>
<tr>
<td>NSW</td>
<td><a href="http://www.ahmrc.org.au">http://www.ahmrc.org.au</a></td>
</tr>
<tr>
<td>VIC</td>
<td><a href="http://www.vaccho.au">http://www.vaccho.au</a></td>
</tr>
<tr>
<td>WEBSITES - Lead Agencies</td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>WA</td>
<td><a href="http://www.ahcwa.org.au">http://www.ahcwa.org.au</a></td>
</tr>
<tr>
<td>SA</td>
<td><a href="http://www.achsa.org.au">http://www.achsa.org.au</a></td>
</tr>
<tr>
<td>NT</td>
<td><a href="http://www.amsant.org.au">http://www.amsant.org.au</a></td>
</tr>
<tr>
<td>TAS</td>
<td><a href="http://www.tacinc.com.au">http://www.tacinc.com.au</a></td>
</tr>
<tr>
<td>ACT</td>
<td><a href="http://www.winnunga.org.au">http://www.winnunga.org.au</a></td>
</tr>
<tr>
<td>National Congress of Australia’s First People</td>
<td><a href="http://www.nationalcongress.com.au">http://www.nationalcongress.com.au</a></td>
</tr>
<tr>
<td>Central Australian Rural Practitioners Association</td>
<td><a href="http://www.carpa.org.au">http://www.carpa.org.au</a></td>
</tr>
<tr>
<td>Council Remote Area Nurses Association</td>
<td><a href="http://www.crana.org.au">http://www.crana.org.au</a></td>
</tr>
<tr>
<td>Royal Flying Doctors Service</td>
<td><a href="http://www.flyingdoctor.org.au">http://www.flyingdoctor.org.au</a></td>
</tr>
<tr>
<td>Careers Australia</td>
<td><a href="http://www.carersaustralia.com.au">http://www.carersaustralia.com.au</a></td>
</tr>
<tr>
<td>NOTE: Carers organisations are also in states and territories</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>WEBSITES - Palliative care associations</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>World Health Organisation - Palliative Care</td>
<td><a href="http://www.who.int/cancer/palliative">http://www.who.int/cancer/palliative</a></td>
</tr>
<tr>
<td>Palliative Care Australia</td>
<td><a href="http://www.pallcare.org.au">http://www.pallcare.org.au</a></td>
</tr>
<tr>
<td>International Association for Hospice and Palliative Care</td>
<td><a href="http://www.hospicecare.com">http://www.hospicecare.com</a></td>
</tr>
<tr>
<td>Palliative Care Nurses Australia</td>
<td><a href="http://www.pcna.org.au">http://www.pcna.org.au</a></td>
</tr>
<tr>
<td>Life and Death Matters (hospice palliative care)</td>
<td><a href="http://www.lifeanddeathmatters">http://www.lifeanddeathmatters</a></td>
</tr>
</tbody>
</table>
### WEBSITES - Pain

<table>
<thead>
<tr>
<th>Website</th>
<th>URL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Pain Society</td>
<td><a href="http://www.apsoc.org.au">http://www.apsoc.org.au</a></td>
</tr>
<tr>
<td>International Association for the Study of Pain</td>
<td><a href="http://www.iasp-pain.org">http://www.iasp-pain.org</a></td>
</tr>
<tr>
<td>American Pain Foundation</td>
<td><a href="http://www.painfoundation.org">http://www.painfoundation.org</a></td>
</tr>
</tbody>
</table>

### WEBSITES - Palliative medicine sites

<table>
<thead>
<tr>
<th>Website</th>
<th>URL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Drugs Information</td>
<td><a href="http://www.palliativedrugs.com">http://www.palliativedrugs.com</a></td>
</tr>
<tr>
<td>Australian and New Zealand Society of Palliative Medicine</td>
<td><a href="http://www.anzspm.org.au">http://www.anzspm.org.au</a></td>
</tr>
<tr>
<td>Royal Australasian College of Physicians</td>
<td><a href="http://www.racp.edu.au">http://www.racp.edu.au</a></td>
</tr>
</tbody>
</table>

### WEBSITES - Chronic Health

<table>
<thead>
<tr>
<th>Website</th>
<th>URL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Council Australia</td>
<td><a href="http://www.cancer.org.au">http://www.cancer.org.au</a></td>
</tr>
<tr>
<td>Cancer Council NT</td>
<td><a href="http://www.cancemt.org.au">http://www.cancemt.org.au</a></td>
</tr>
<tr>
<td>Cancer Council ACT</td>
<td><a href="http://www.actcancer.org.au">http://www.actcancer.org.au</a></td>
</tr>
<tr>
<td>Cancer Council SA</td>
<td><a href="http://www.cancer.sa.org.au">http://www.cancer.sa.org.au</a></td>
</tr>
<tr>
<td>Cancer Council NSW</td>
<td><a href="http://www.cancercouncil.org.au">http://www.cancercouncil.org.au</a></td>
</tr>
<tr>
<td>Cancer Council VIC</td>
<td><a href="http://www.cancervic.org.au">http://www.cancervic.org.au</a></td>
</tr>
<tr>
<td>Cancer Council TAS</td>
<td><a href="http://www.cancertas.org.au">http://www.cancertas.org.au</a></td>
</tr>
<tr>
<td>Cancer Council QLD</td>
<td><a href="http://www.cancerqld.org.au">http://www.cancerqld.org.au</a></td>
</tr>
<tr>
<td>American Cancer Society</td>
<td><a href="http://www.cancer.org/index">http://www.cancer.org/index</a></td>
</tr>
<tr>
<td>PDQ - United States National Cancer Institute</td>
<td><a href="http://www.cancer.gov/cancerinfo/pdq/cancerdatabase">http://www.cancer.gov/cancerinfo/pdq/cancerdatabase</a></td>
</tr>
</tbody>
</table>
### WEBSITES - Chronic Health

<table>
<thead>
<tr>
<th>Chronic Health Category</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peter MacCallum Cancer Centre</td>
<td><a href="http://www.petermac.org">http://www.petermac.org</a></td>
</tr>
<tr>
<td>Virtual Cancer Centre</td>
<td><a href="http://www.virtualcancercentre.com">http://www.virtualcancercentre.com</a></td>
</tr>
<tr>
<td></td>
<td><a href="http://www.fightdementia.org">http://www.fightdementia.org</a></td>
</tr>
<tr>
<td></td>
<td><a href="http://www.journalofdementiacare.com">http://www.journalofdementiacare.com</a></td>
</tr>
<tr>
<td>Cardiovascular Disease</td>
<td><a href="http://www.heartfoundation.org.au">http://www.heartfoundation.org.au</a></td>
</tr>
<tr>
<td>Chronic Kidney Disease</td>
<td><a href="http://www.kidney.org.au">http://www.kidney.org.au</a></td>
</tr>
<tr>
<td>Asthma</td>
<td><a href="http://national.asthma.org.au">http://national.asthma.org.au</a></td>
</tr>
<tr>
<td>Palliative care for sick lungs</td>
<td><a href="http://www.asthmaaustralia.org.au">http://www.asthmaaustralia.org.au</a></td>
</tr>
<tr>
<td>Renal</td>
<td><a href="http://renalresource.com">http://renalresource.com</a></td>
</tr>
<tr>
<td></td>
<td><a href="http://renalsociety.org">http://renalsociety.org</a></td>
</tr>
<tr>
<td>Australian Liver Foundation</td>
<td><a href="http://liver.org.au">http://liver.org.au</a></td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td><a href="http://www.aids.org">http://www.aids.org</a></td>
</tr>
<tr>
<td></td>
<td><a href="http://www.cdc.org/hiv">http://www.cdc.org/hiv</a></td>
</tr>
<tr>
<td></td>
<td><a href="http://avert.org">http://avert.org</a></td>
</tr>
<tr>
<td>Musculoskeletal Conditions</td>
<td><a href="http://www.arthritisaustralia.com.au">http://www.arthritisaustralia.com.au</a></td>
</tr>
<tr>
<td></td>
<td><a href="http://www.bonehealth.org.au">http://www.bonehealth.org.au</a></td>
</tr>
<tr>
<td>Degenerative conditions of aging</td>
<td><a href="http://www.fightdementia.org.au">http://www.fightdementia.org.au</a></td>
</tr>
</tbody>
</table>
**APPENDIX 1**

**Before the placement:**
- Read this learning guide
- Read through and mark off this Checklist as you work through your clinical placement
- Complete your PEPA pre-placement learning plan including your goals and strategies (2.3 of this guide) and return a copy, or submit online, to your PEPA manager
- Contact the PEPA Manager regarding any administrative issues
- Make telephone contact with your Host site to confirm your attendance (at least one week before your placement)
- Ensure you know the address, contact details and where to meet at your Host Site

**At the commencement of the placement:**
- Review your learning goals with your Mentor
- Identify activities/opportunities to achieve learning goals i.e. ward rounds, hand over, case conferencing, team meetings, family meetings, home visits, in-services etc.
- Prepare a tentative schedule with your Mentor that includes time to observe multidisciplinary approach to care and an opportunity to network with staff from other disciplines.
- Establish regular meeting times and a way for you to be contacted throughout the day

**During the placement:**
- Seek out resources and sources of information as required
- Be mindful of behaviours and attitudes
- Take time to reflect, read patient records (as appropriate), policies, pamphlets, PEPA Learning Guide etc.
- Seek opportunities to debrief and review goals at the end of each day
- Your mentor will give you ongoing feedback as appropriate
On completion of the placement:

☐ Debrief and review of goals with your Mentor

☐ Discuss your planned workplace activity with your own workplace manager (must be implemented in their service within three months of completing a PEPA placement)

☐ Complete your PEPA Post Placement Workplace Activity Plan and Reflection (4.4 of this guide) and return a copy, or submit online, to your PEPA manager

☐ Ensure the Placement Completion Form (Appendix 2) is signed off by EACH Mentor at the different Host Sites for your continuing professional development CPD points and for your PEPA manager to site that you have completed your placement. For further information re CPD points, visit http://www.ahpra.gov.au

☐ Build on your workplace’s palliative care network at each opportunity

NOTES:
APPENDIX 2

DOCS TO RETURN FOR YOUR PLACEMENT

PARTICIPANT BACKGROUND KNOWLEDGE & EXPERIENCE

(complete and forward to your mentor with your pre-placement learning plan)

It will be helpful for your mentor and host site to understand your background knowledge and experience, as well as what you hope to learn from your PEPA placement. Print this page and return to your PEPA manager who will forward it on to your host site so that they know how to better assist you during your placement.

What is your background in terms of professional experience and qualifications?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

What previous experience and/or education have you had in palliative care?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

When completing your PEPA application, you completed questions to assist in developing an awareness of what your palliative learning goals were and what you would like to take away from your Placement.

Attach a copy of the Goals and Objectives from your application here.
YOUR PRE-PLACEMENT LEARNING PLAN

Think about your learning needs and goals and how you will be able to meet these. Think about which people at the Host site will be able to help you achieve your goals and how they might be able to do this. Remember, you only have a few of days at the host site so you will need to plan to maximise your learning.

Below are some activities of palliative care facilities. These may be helpful with your pre placement learning needs and plan. Circle activities you would like to experience in the end of life (EoL) care path and discuss with your Mentor.

What would you like to see or experience during your placement?

<table>
<thead>
<tr>
<th>Ward Rounds</th>
<th>Handover</th>
<th>Case Conferencing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Team meetings</td>
<td>Family meetings</td>
<td>MDT meeting</td>
</tr>
<tr>
<td>Training or Inservice</td>
<td>Assessments</td>
<td>ACP / Bereavement</td>
</tr>
<tr>
<td>Roles of diverse disciplines</td>
<td>Different EOL stages</td>
<td>Personal Cares</td>
</tr>
<tr>
<td>Discussions on addressing troubling symptoms/ difficult conversations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visit service settings - hospital, community, specialist service, admissions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Body cares after finishing up/death (washing and laying out)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Other:** ........................................................................................................................................

**Is there anything that may be inappropriate for you to participate in?** ........................................................................................................................................

**Is there anything you are unsure or uncomfortable about?** ........................................................................................................................................

**Your name** ........................................................................................................................................

**Signature** ........................................................................................................................................

**Date** ........................................................................................................................................
REFLECTION OF LEARNING

Now you have time to reflect, go back to Section 2 and review each of your goals in your learning plan.

Have you met your initial goals? If they have changed, what may have influenced this?

List the key areas of learning and new skills you have acquired during your workplace placement.
Which of this new knowledge and new skills will you be able to take back to your own workplace?

Think about the resources and other members of your workplace will help you to integrate what you have learnt at your workplace.
### 4.2 Placement Completion Form

*(Return a copy to your PEPA Manager with 14 days)*

Participant’s name: 

AHPRA number: 

Name of own workplace: 

Postal Address: 

Phone: 

Email: 

<table>
<thead>
<tr>
<th>Number of Hours Completed at site</th>
<th>Signature</th>
<th>Print name</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your PEPA manager</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Host Facility 1 Name and Address</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Host Facility 1 Your mentor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Host Facility 2 Name and Address</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Host Facility 2 (if applicable)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Host Facility 2 Your mentor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Host Facility 3 Name and Address</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Host Facility 3 (if applicable)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Host Facility 3 Your mentor</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
WORKPLACE ACTIVITY PLAN

Outline the activity you will undertake

How will the activity influence the care of a person with a life limiting illness in your or your colleagues care?

Where will the activity be conducted and who will be involved?
How will you evaluate the activity?

Date of implementation: ____________________________

Participant’s signature: ____________________________

Date: ____________________________

Workplace Manager’s signature: ____________________________

Date: ____________________________
POST WORKPLACE ACTIVITY REFLECTION

At three months post placement, you will be asked to complete a questionnaire about your PEPA experience, by your PEPA state manager. This is an important part of your learning experience and for the evaluation of the PEPA project. The evaluation will ask you to consider:

What knowledge and skills have you gained from your PEPA placement?
How have your own practices changed in the palliative approach?
What changes have occurred at your workplace since your placement?
In what way did your Post Placement activity influence your workplace practices?
The footprints are the journeys taken to and from health services and end of life care services (pictured at the top of the page), where health staff gather to share important information and resources about the life limiting condition and end of life care (shown by the helping hands coming in from the sides).

The dotted circles at the bottom of the picture represent families and communities. Many have come in preparation for Sorry Business. Above this is the coolamon or canoe, both used for carrying items (food, babies or people) to nurture and support life.

The oval shapes in the centre represent moving through different stages in life’s journey with the energy of the spirit as it leaves the journey in the last shape. The spray of cascading white dots is symbolic of numerous things: the tears that come with Sorry Business, the dhari and the spirit leaving the life journey and travelling back to the spirit world. As Sorry Business starts with men and women, you can see the spirit meeting with the past, present and future (rippling effect).

END OF LIFE JOURNEY

Michael is an Aboriginal artist and craftsman; a cultural educator and consultant. Michael grew up in Charleville, SW QLD and is a descendent of the Kullilla tribe from the Thargomindah/Eudlo region (on his father’s side) and from the Muruwari People from Goodooga/Brewarrina region NW NSW (on his mother’s side).

Recognising Aboriginal cultures and Torres Strait Islander cultures
Respecting people, beliefs and choices
Honouring the past, the present and the future