

PEPA

Program of Experience in
the Palliative Approach

Funded by the Australian Government through the National Palliative Care Program

The Program of Experience in the Palliative Approach Learning Guide

**General Practitioners
and
Rural and Remote Medical Practitioners**

Version 2.1

THE NATIONAL
PALLIATIVE CARE
PROGRAM



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1. Introduction

Welcome to the Program of Experience in the Palliative Approach (PEPA).

Palliative care is an integral part of general practice, and is a skill virtually any doctor who has clinical responsibilities will need at some stage. Having an understanding of the principles of palliative care and mastery of several strategies will give you the tools to manage many of the problems that patients and families face.

PEPA is an initiative of the Australian Government Department of Health and Ageing that aims to improve the quality, availability and access to palliative care for people with life-limiting illness, and their families.

To achieve this aim, PEPA provides supervised clinical placements and structured learning activities for medical staff at specialist palliative care services. Where possible, your clinical placement at the palliative care service will include experience in the following settings:

- Inpatient palliative care, which can provide experience in the ongoing management of patients, case conferencing and the role of the multidisciplinary team;
- Acute Hospital Consultancy, which involves experience in the management of patient and family / carer needs during the transition from curative to palliative care and management of complex acute problems; and,
- Community practice, which will provide experience in management of patient and family / carer needs in the community, and develops knowledge of resources and equipment available for care in the home.

This workbook has been designed to provide a learning resource to help you to gain the most from your participation in PEPA. It will act as a reference and direct you to sources of information that should enable you to develop your knowledge and skills in palliative care.

The learning guide is divided into six sections:

1. Introduction
2. Preparation for PEPA: This section is important to help define your learning goals and identify how to ensure you achieve these goals in this program.
3. Key Topics in Palliative Care: This section includes information to assist you to manage the common problems you will face when caring for patients with life-limiting illness. For each of the topics covered in the workbook, you will be provided with a brief description of the key issues in assessing and managing the issue. This will be followed by a series of questions and learning activities to help guide your learning. You can complete these activities during your clinical placement. The information can also be kept as a useful resource once you have completed your placement.

4. Suggested Clinical Activities: This section provides some suggested activities that will assist you to achieve your learning goals.
5. Applying Your Learning: This section includes a summary of the types of activities that you may wish to undertake to help apply your learning in your own practice.
6. Palliative Care Resources: This section includes a summary of resources to assist you in providing palliative care.

The tabbed sections include modules and attendance forms for professional development points. The RACGP module will help record valuable information to track your learning and that will assist you to provide palliative care.

For allocation of professional development points from the professional colleges:

ACRRM Fellows should complete the record of attendance, (Tab 1), which includes your details and return a copy of this to the PEPA National Coordinator who is the administrator for the allocation of professional development points from this college.

RACGP Fellows should complete the RACGP module (Tab 2), and return a copy of all pages to the PEPA National Coordinator who is the administrator for the allocation of quality assurance and continuing professional development points.

Along with this workbook, you will be given a copy of the *Therapeutic Guidelines: Palliative Care Version 3, 2010* as a reference book.

A note from the author

Palliative care is enormously rewarding and challenging. It is also a privilege to participate in the last part of a patient's life. Medical practitioners in the early stages of their training and professional lives can be quite intimidated by the thought of caring for patients with a life-limiting illness and their families.

Two things help practitioners to feel more comfortable in dealing with this reality. The first is to realise that the aim of palliation is to control the symptoms of the illness to the best extent possible, to minimise their impact on the patient and to improve the patient's and family's quality of life. This is a major departure from the curative model most doctors are familiar and comfortable with, but allows practitioners to realise that the progression of a symptom, as a result of advancing illness, is not failure on their part. The second is that the patient, in consultation with the family, sets goals of care, and they may not necessarily be the ones the doctor would set for the patient. They are often couched in terms of function, such as, *I want to be able to walk to the shops*, or events such as, *I want to be able to get to my grand-daughter's wedding*. The doctor's role is to try to help the patient achieve these goals, through symptom control and by facilitating the use of appropriate support mechanisms.

Medical practitioners often become more comfortable with palliative care the more they perform it. The first few times can be difficult, and these difficulties may deter further attempts at providing palliative care. Stick with it. You can really make a difference.

Enjoy your participation in PEPA.

2. Preparation for PEPA

2.1 Identifying your learning needs

A national palliative care survey of GPs ⁽¹⁾ noted the issues which caused the greatest degree of concern for GPs were:

- Communication difficulties with relatives;
- Communication difficulties with patients;
- Managing non-pain symptoms – eg dyspnoea, nausea;
- Managing pain symptoms; and
- Utilising local palliative care resources.



Activity 1

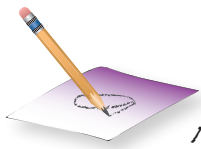
Think back to your experiences in caring for palliative care patients. What were the issues you found most difficult to manage? Are the issues identified in this Australian study similar to your own? What were the issues around which you wish you had more knowledge?



Activity 2

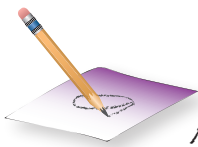
Please identify up to five problems you have had in managing palliative care patients. Are these reflected in the learning objectives you wish to pursue during your placement?

1.
2.
3.
4.
5.



Activity 3

Consider how your workplace currently provides care to assist patients and their families with the issues you have identified above. Are there any 'burning issues' that should be improved?



Activity 4

Discuss these issues with your work team / employer. Can you identify any activities / strategies that could be implemented to improve outcomes for patients with life-limiting illness and their families?

2.2 Reviewing your learning objectives

Your participation in PEPA should enable you to:

- Demonstrate a clear understanding of the principles of palliative care;
- Identify the needs of palliative care patients;
- Identify the role of practitioners in your field in managing common problems faced by patients with life-limiting illness and their families;
- Recognise your own knowledge base / scope of practice with regard to optimal palliative care provision; and
- Identify personal coping strategies for effective management of stress related to working in this field.



Activity 5

Review the objectives you wrote down in your application to this program. After considering the program objectives outlined above, and your responses to the questions in the previous section, do you wish to add to / modify your objectives?

Think how you might use your supervised clinical placement to achieve your learning goals. Remember, you only have a few days at the service. Think about which people at the Palliative Care Service will be able to help you achieve your objectives.

Use the table below to rewrite your learning objectives and to suggest strategies, or individuals you might work with to achieve them. Where relevant, you may also like to make a note of the particular setting (e.g. inpatient; consultancy service; community) where you might use these strategies.

| Your Key Learning Objectives | Strategies |
|-------------------------------------|-------------------|
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2.3 Your Pre-Placement Activities

The table below lists the activities that you should complete before you commence your placement.

Before Your Visit

- Complete and return your PEPA pre-placement evaluation
- Clearly identify your personal learning objectives
- Complete activities 1–5 in this learning guide before you attend your placement
- Contact the PEPA manager regarding any administrative issues
- Contact your medical mentor at the palliative care service to confirm your attendance (at least one week before your placement)
- Discuss your learning objectives with your mentor at the palliative care service and negotiate as required
- Identify the palliative care service providers in your local area (you may like to record these below)



Activity 6

List the members of your local palliative care team

(You may wish to include allied health staff from the multidisciplinary team who consult with patients and families who require a palliative care approach - for example social workers or occupational therapists.)



| Name | Job Title | Role | Contact Details |
|-------------|------------------|-------------|------------------------|
| | | | |
| | | | |
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3 Key Topics in Palliative Care

3.1 Definition of Palliative care

The World Health Organization⁽²⁾ defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

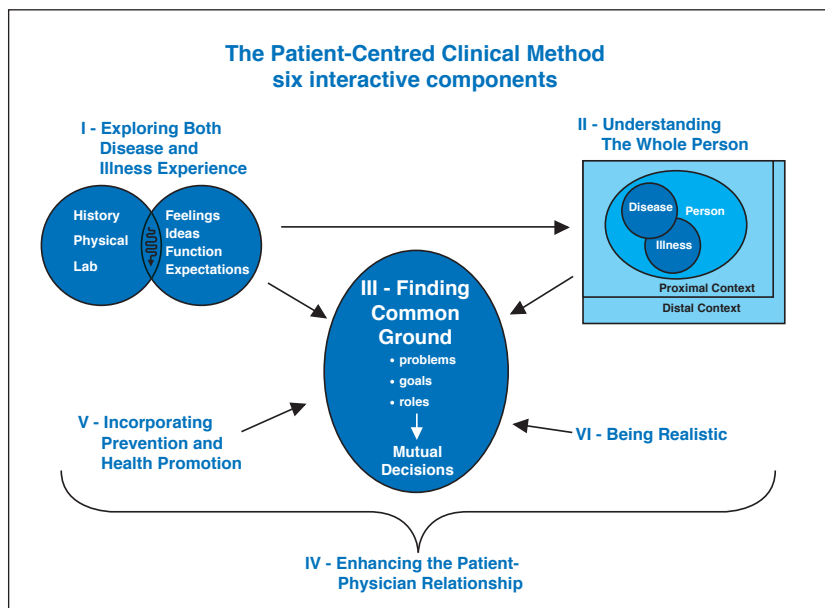
Additional definition of terms and the *Standards for Providing Quality Palliative Care for all Australians* are contained in Appendices 1 and 2.

3.2 Determining goals of care: Seeing the big picture

The nature of the illness experience is complex. This complexity is easy to recognise in the palliative care setting. The founder of modern palliative care, Dame Cicely Saunders, described the concept of "total pain". In essence, this concept helps explain that the severity of physical symptoms, such as pain, can be influenced by multiple factors. For example, difficult social circumstances, such as poor family relationships or financial difficulties, can influence symptoms and factors such that these need to be managed as actively as the physical problems. It is essential that medical practitioners understand this complexity, and have some means of holistically assessing the patient and the family.

Consider the clinical method developed by Stewart et al. (2003) to assess patients and come to agreed management strategies. There are several components to understanding the situation, which are then brought together in a shared decision – making process.⁽³⁾ (Figure 1)

Figure 1. The Patient Centred Clinical Method.



Reproduced with permission:

Stewart MA, Brown JB, Freeman TR, 2003, Patient-centered medicine: transforming the clinical method. 2nd ed. Abingdon: Radcliffe Medical.

- The first component is the disease itself, into which is woven the experience of suffering from the disease: the so-called “illness experience”. The usual assessment of the history, physical examination and laboratory findings describe the disease process. However, there is also the experience of this disease for the patient – the illness experience. What is it like to be so ill that it is difficult to get out of bed? What are the frustrations and trials? For the clinician, observation of the patient weaves backwards and forwards between describing the disease and hearing the illness experience.
- The second component is the effect of the disease / illness experience on the individual. What does the illness do to the other parts of the person? How does the illness impact on how the person does the business of life? How do the person’s innate characteristics – personality, resilience, interests and skills - impact on the way they cope with their illness / disease?

Part of the second component is how the person interacts with those closest to him or her. How do the patient’s family, workplace and close social contacts impact on the person while ill?

A range of other factors also need to be considered to ensure that the holistic needs of the person and their family can be addressed. What is the role of factors like culture, access to money and resources, and the efficiency or otherwise of the health system in dealing with this person’s issues? For example, caring for Indigenous palliative care patients, or patients from a culturally and linguistically diverse background requires understanding of their cultural norms. It may be necessary to change the way a service operates to account for these. (Further information about caring for Aboriginal people and people from CALD backgrounds is included in Sections 3.4 and 3.5)

- The third component is the process of decision making. The process of developing mutually agreed solutions to the problems the person faces involves understanding of the patient by the doctor, and by the patient of what the doctor and other health professionals can and cannot do.
- Part of seeing the big picture is also considering the effect of the patient's life-limiting illness on the family and caregiver. The needs of family members may differ, some may require little assistance while others may require practical and psychological support as they experience the emotional and physical burden of caring for their family member. The *clinical practice guidelines for the psychosocial care of adults with cancer* (NHMRC, 2003) highlights that if a parent has advanced cancer, the needs of children and adolescents may require specific attention as parents may not be able to recognise or respond to the child's emotional needs. ⁽⁴⁾



Activity 7

The website <http://www.healthtalkonline.org/> has collected video clips and audio tapes of real patients talking about their experience of suffering a range of illnesses, including terminally ill patients. Take time to look at this site.

Follow these steps to view a video clip of a patient describing the feeling they experienced upon being diagnosed with a terminal illness.

Open site <http://www.healthtalkonline.org/>.

Click on [Cancer](#).

Click on [Lung Cancer](#). (in the left hand menu)

Click on [Thoughts on recurrence, death and dying](#)

Click on '[He has a lot to live for and the thought of possibly dying relatively young, leaving others is very difficult.](#)' (interview LC44). You may need to install flash to view video. Alternatively, you can read the transcript.

How does the patient describe their experience? What does the patient describe as their main concerns and worries?

You may wish to view other patients talking about their experiences of living with a life-limiting illness in the area entitled, [Living with dying](#) (to access this page go back to the homepage and click on the box [Dying & bereavement](#) then follow the links).

3.3 Communication of Prognosis and End-of-Life Issues

Being able to discuss prognosis and end-of-life issues is a vital skill for health care professionals caring for patients with progressive life-limiting illnesses, and their families. Patients and their caregivers need to be adequately informed to participate optimally in decisions about their treatment and care, to set goals and priorities, and to prepare for death. It is the clinician's role to provide pertinent information in a way that assists patients and their families to make appropriate decisions, be informed to the level that they wish, and cope with their situation. The following clinical guidelines have been developed to assist clinicians with this difficult and important task: *Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers* (Clayton et al., 2007)⁽⁵⁾.

The key recommendations of these guidelines are conveyed by the acronym PREPARED.

P – Prepare for the discussion

R – Relate to the person

E – Elicit patient and caregiver preferences

P – Provide information tailored to the individual needs of both patients and their families

A – Acknowledge emotions and concerns

R – (Foster) realistic hope

E – Encourage questions and further discussions

D - Document



Activity 8

Take time to read through the *Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers* (Clayton et al., 2007)⁽⁵⁾. Read through Boxes 1 to 16 and highlight specific phrases that fit with your style and with which you might feel comfortable using in your practice.

3.4 Providing culturally appropriate palliative care for Indigenous Australians

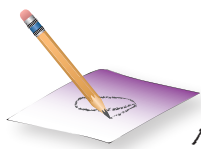
This is an enormously complex area.

A few brief points to consider:

- Communicate with the patient, their family and community in a sensitive way that values their cultural difference.
- Work with Aboriginal & Torres Strait Islander organisations and Indigenous health workers as they will have knowledge of the cultural background. (Make a point of finding out what is culturally appropriate.)
- The Aboriginal & Torres Strait Islander patient's connection with their country is profound. All avenues should be considered to have care provided in their own community if this is what the patient and family wish.
- Urban Aboriginal & Torres Strait Islander people may adhere to some, all or none of the traditional ways.

If your practice includes individuals who come from Indigenous communities, it will be worth obtaining a copy of resources commissioned by the Australian Government to support health professionals' work in this field.

Mungabareena Aboriginal Corporation, Wodonga Institute of TAFE and Mercy Health Service Albury (Palliative Care) (2004) Providing Culturally Appropriate Palliative Care to Indigenous Australians Resource Kit. Canberra: Rural Health and Palliative Care Branch Australian Government Department of Health and Ageing. Available: <http://www.caresearch.com.au/caresearch/WhatisPalliativeCare/NationalPalliativeCareProgram/IndigenousPalliativeCareProject/tabid/86/Default.aspx>



Activity 9

Find out the name and contact details of the local Aboriginal & Torres Strait Islander organisation / person who can assist with cultural support for you and the patient and family.

Make a note of some specific considerations you would take into account in your practice when caring for an Aboriginal & Torres Strait Islander patient who requires palliative care.

3.5 Providing culturally appropriate palliative care for people from Culturally and Linguistically Diverse (CALD) backgrounds

The way culture can influence a person's experience of death and dying is complex. Some important points to consider are:

- Treat each person as an individual. There can be wide variations in beliefs and values both between and within ethnic groups. It is important to avoid making assumptions about patients from other countries and avoid stereotyping.
- Seek to understand other people's needs. In most cases simply asking the patient or family about what is culturally appropriate behaviour is a valuable initial step.
- Interpreters, cultural brokers and/or translated resources may be appropriate.



Readings

For more information please refer to the following resources:

Migrant Information Centre (2009). Palliative Care for Culturally and Linguistically Diverse Communities. Melbourne. Available: www.miceastmelb.com.au

The Metropolitan Acute Palliative Care Resource (2007). Supporting special needs groups (webpage). www.mapcare.org.au

Palliative Care Australia (2009). Palliative care and culturally linguistically diverse communities: position statement (draft). Available: <http://www.palliativecare.org.au/Default.aspx?tabid=1942>

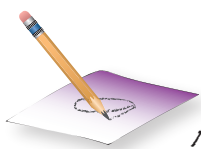
3.6 Respect and utilise the skills of the team

Grande ⁽⁶⁾ has shown that the perceptions of doctors and nurses differ from those of the patients in terms of which symptoms are most troublesome. Consider why this would occur.

Doctors may be more confident in caring for pain, sleeplessness, depression and anxiety. Nurses may be more confident in managing bowel and bladder problems, unpleasant smells and wounds. That is, confidence relates to what different professionals are able to treat well. Moreover, doctors may recognise the presence of symptoms in patients less often than the patients actually report them. All professionals carry a degree of bias – they may fail to report on symptoms they can do little about, and may over-report symptoms where they can offer some treatments. The same comments can be made for a wide range of allied health providers, including pastoral care workers.

It makes sense therefore, to use a team approach, gaining the broad variety of skills that the multidisciplinary team can provide.

Because palliative care has the input of many service providers, it is important that the team is coordinated. This task may fall to you as the GP or supervising medical officer. It is important; therefore, that you can identify strategies and resources that will assist you in ensuring care is coordinated for the patient and family.



Activity 10

Take the time during your placement to meet with members of the what multidisciplinary team. Talk to them about their roles in palliative care, when their expertise should be called upon and what would be the best way for you to access this expertise in your local district.

Observe how the team functions.
Consider the following questions:

- How are care plans developed, recorded and disseminated?
- Has there been a written plan developed?
- Who allocates responsibilities / tasks?

- How do they utilise the team approach to assist with family issues?
- Is use made of the Enhanced Primary Care, Medicare Benefits Scheme item numbers?
- How could your local team assist you should you take on the care co-ordination role?

See if there is the opportunity to sit in on a family meeting, where future care for the patient is negotiated.

What is the purpose of the family meeting?

What strategies are used to achieve the goals of the meeting?

Notes:



Activity 11

Think again about your local palliative care service. Who are the members of that team? What skills do they offer patients? From the observations and reflections you make during your placement, use the following headings to record specific strategies you will use to promote:

- Effective multidisciplinary care
- Continuity of care

3.7 Principles of assessment of pain and other symptoms

A trap when dealing with palliative care patients is the failure to perform an adequate assessment of the patient's symptoms. Unconsciously, some practitioners may argue the following:

- history taking takes time;
- physical examinations may be uncomfortable; and
- the patient is very ill - why put them through complete examinations when it is obvious where the issue lies?

This can be a serious mistake. The efficacy of patient's treatments depends to a large degree on the accuracy of the diagnosis. Not all symptoms are caused by the life-limiting illness. Not all pains are the same nor will they all respond to morphine. There are different forms of constipation, which respond to different forms of treatment.

There may be a place for investigations in patients who are very ill. They are warranted where those investigations will determine which of several alternative diagnoses is the correct one, and where major differences in treatment approach and improved symptom relief might result.

Example:

Michael L. has advanced renal cell carcinoma. He has known lymphadenopathy in his thorax, and has dyspnoea on exertion. He also has known atrial fibrillation. Chest X-Ray shows hilar lymphadenopathy, and apparent compression of the lower trachea. He was admitted to hospital by his GP for consideration of local radiotherapy or possibly a stent. The hospital performed a CT scan, which showed the trachea was not compressed. Comparison with old films showed no change in the size of the lymphadenopathy in six months. ECG revealed atrial fibrillation with an apical rate of 150 beats per minute - more than enough to explain the man's dyspnoea. His anti-arrhythmic therapy has been modified, and he remains well six weeks later.



Activity 12

What assumptions did the GP make about the cause of Michael's dyspnoea?

Could the GP have conducted further assessment at the surgery to clarify the diagnosis? What factors might have led the GP to the clinical decision to send the patient on for admission without further assessment?

3.8 Assessing and Managing Pain

Pain is a common symptom encountered by patients with life-limiting disease, along with other symptoms such as cachexia, fatigue and appetite disturbance. Pain is probably the most feared symptom for patients and family members.

Below are some important issues to consider.



Read the chapter entitled Pain, *Therapeutic Guidelines Palliative Care*, pp pp 183 - 227

The section on pain assessment contains important information on the assessment and management of pain in palliative care. Note the overarching principles *Therapeutic Guidelines Palliative Care*, p 185.

Please note the following:

- Pain is subjective, and the severity of the pain described by the patient must be taken seriously.
- The pain of cancer and other life-limiting disease differs markedly from the pain of injury or acute disease.
- Acute pain warns the person that acute injury has occurred, and that remedial action is essential to repair the injury.
- Ongoing or refractory pain sends similar unpleasant sensations to the body, with or without the presence of progressive injury; therefore the pain is not serving the same useful purpose.

The immediate action required is the relief of the pain.

- More than one kind of pain may exist simultaneously.
- The phase of the illness, the nature of the pain and its location will largely determine the treatment employed.
- Non-drug treatments can contribute to the patient's comfort very significantly.
- Many patients can get by with a reduced dose of opioid by the judicious use of adjuvant medications.

There are three basic types of pain: nociceptive, neuropathic or neurogenic, and psychosomatic. The importance of distinguishing which form of pain is present is that the treatment differs for each. There can be elements of the different pain types in each case. There are clear clinical features of each, which are set out in *Therapeutic Guidelines Palliative Care*, pp 189 - 190.

A simplified version of this information is presented in Table 1.

| Table 1 Nociceptive and Non-nociceptive Pain | |
|---|--|
| <p>Nociceptive Pain</p> <p>TYPES:</p> <p>Somatic Nociceptive Pain</p> <ul style="list-style-type: none"> • Stimulation of nociceptive receptors in the skin, myofascial structures and bone <i>pain is constant and well localised</i> • variation in pain intensity related to body position, movement & time eg. Bone pain <p>Visceral Nociceptive Pain</p> <ul style="list-style-type: none"> • sensory input from visceral nociceptive structures (organ capsules & hollow organs) • two main forms: • capsular stretch or pressure pain (seen in liver secondaries or a primary kidney cancer) <i>pain described as a dull ache, "deep" or a pressure</i> • colicky pain (due to obstruction of a hollow viscus) <i>pain described as intermittent and griping</i> | <p>Non-nociceptive Pain</p> <p>TYPES:</p> <p>Neuropathic Pain</p> <ul style="list-style-type: none"> • Peripheral nerve pain due to stretching or compression of sensory nerve fibres by extrinsic mass, neural infiltration, or injury to central structures • Central neuropathic pain Injury at any level of the nervous system may produce a cascade of changes in the CNS resulting in permanent changes e.g. in phantom limb pain or postherpetic neuralgia. <p><i>Neuropathic pain is relatively insensitive to morphine alone and presents as shooting (like electric shocks) or constant pain associated with sensory changes, such as burning or pins and needles sensations or allodynia (light touch is felt as unpleasant or as actual pain).</i></p> <p>Psychogenic Pain</p> <p>Most pain has some psychogenic component, however, pain of any origin can be modified markedly by co-existing psychiatric disease and psychopathology.</p> |

Adapted from Blue Book of Palliative Care: Evidence based guidelines for primary practitioners. (7)

It is very helpful to use relatively objective measures of pain intensity so the efficacy of treatment can be evaluated. Examples of scales used for this are in *Therapeutic Guidelines Palliative Care*, pp 371 - 374.



Activity 13

What are the benefits of assessing the intensity of pain with a pain scale? Can you think of key questions that will distinguish between nociceptive pain and neuropathic pain?

Most pain has a psychogenic element to it. How would you recognise this and how would you go about alleviating this?

3.8.1 Commencing sustained-release, long-acting opioids



Readings

Before completing this section, you may like to reread the relevant section about pharmacological treatment of pain: *Therapeutic Guidelines Palliative Care*, pp 199 - 217

Since most pain types require regular opioid, a core skill in pain management is the ability to initiate long-acting opioids. It is essential that you learn how to do this.

Morphine remains the gold standard for pain relief. In the situation where a patient cannot tolerate morphine, the dose requirements for other opioids are often calculated in relation to the equivalent dose of morphine.

There are many opioids available in Australia. It is not practicable to be completely au fait with them all. Get to know one or two really well, and consult with specialist palliative care teams if you need advice.

The key steps are:

- Address fears and misconceptions around opioids, particularly addictive potential, wanting to have “something in reserve”, fear of respiratory depression.
- Ensure that the type of pain that the patient has is responsive to opioids. In particular, neuropathic pain may not respond to opioids well.
- The dose of opioid should be titrated to effect. Dosing should commence with an immediate release, short-acting opioid. The initial dose will depend on:
 - o previous medication used
 - o the severity of the pain
 - o the size and age of the patient
 - o the patient’s renal and hepatic status.

If there has been minimal exposure to opioids in the past, start with 2 mg – 5 mg (for an elderly patient) or 5mg – 10 mg (for a younger, larger patient) orally of liquid morphine “Ordine” every 4 hours (p 205).

For exacerbation of an existing pain already requiring opioid analgesia, or a new pain requiring extra treatment, calculate the equivalent dose of morphine using the conversion table in *Therapeutic Guidelines Palliative Care*, p 105, pp 107 - 116. Then calculate the 24 hour dose of morphine the patient is currently taking. Increase this by approximately 25%, and reconvert to the new dose of the form they are taking - if you wish to continue using the current drug.

Dose reduction may be required if there is renal impairment or severe liver disease. If serum creatinine = > 0.14 mmol/L it would be prudent to use a drug other than morphine, as its metabolites are excreted renally. Alternatives include fentanyl and hydromorphone.

Have prn opioids available for breakthrough pain, and encourage its use. A typical breakthrough dose is one-half (1/2) of the four hourly regular dose – ie one-twelfth (1/12) of the 24 hour total. The patient should be advised that this dose can be used 1-2 hourly as required for breakthrough pain.

It is essential to educate the patient and caregiver about the drug and any possible short term side effects they may experience, providing contact details for advice or assistance, if they are concerned about any issues.

Once the pain has stabilised using the immediate-release morphine, the medication can be changed to a sustained-release form.

To calculate the sustained-release, long-acting morphine:

Calculate the total morphine intake in 24 hours by adding the regular doses to the breakthrough doses.

- Start the patient on the sustained-release form nearest in strength to the daily tally (this will either be a single daily dose preparation eg MS Mono; Kapanol or bd preparations eg MS Contin with half the daily dose delivered with each dose – (see *Therapeutic Guidelines Palliative Care*, pp 206 - 207.)
- When commencing the sustained-release form, give the first dose at the same time as the last dose of immediate-release morphine to cover the patient's analgesic requirements during the time it takes to achieve a therapeutic level of the new medication.
- Recalculate the dose of the breakthrough and advise the patient and family members that this can be continued to be used up to second hourly for breakthrough pain.

Don't forget to start a regular laxative!

The following short case study shows how you might initiate long-acting morphine for pain management.

Mervyn J is a 67 year old man who has persistent lower abdominal pain from advanced colon carcinoma with localised pelvic spread. You decide he has visceral nociceptive pain, and that regular morphine is indicated. He has liver function tests at the upper limit of normal, and normal renal function (serum creatinine 0.10 mmol/L). You commence him on 5 mg liquid morphine 4 hourly, and prescribe breakthrough doses of 2.5 mg of liquid morphine. After 48 hours he returns for review. He has required 3 breakthrough doses each day. Mervyn states that his pain is relieved and on questioning reports that he has not been drowsy on this amount of morphine.

His daily intake of morphine was:

$6 \times 5\text{mg} = 30\text{mg}$ (regular doses), and

$3 \times 2.5\text{mg}$ breakthrough doses = 7.5mg.

Total 37.5 mg morphine per day.

The sustained –release dose prescribed MS Contin 20 mg (10mg x 2 tabs) bd = 40mg over the 24 hours. You prescribe MS Contin 10 mg, 2 tabs twice daily. You keep the breakthrough dose at 2.5mg for the time being. He is commenced on docusate (coloxyl) and senna, 2 tabs at night.



Activity 14

What were the variables the doctor took into account when determining the initial dose of Liquid Morphine (Ordine)?

How would you advise the patient to record opioid intake?

As stated earlier there are many types of opioids and their use should be made on patient assessment considering the efficacy of the opioid in different situations (eg renal failure). Also, choose medications that can be administered by different routes.

For example,

- Morphine can be delivered by oral liquid, sustained-release preparations, tablets, capsules and parenterally.
- Oxycodone has a higher bioavailability than morphine and can be delivered by immediate-release oral tablets, suppositories for per rectal administration, and sustained-release tablets.
- Fentanyl is less constipating than morphine. It has advantages for people with renal disease. Fentanyl can be delivered by transdermal patches and parenterally. Dosing using the patches is less flexible. The smallest patch is equivalent to 60 – 100mg of oral morphine daily.
- Hydromorphone is more potent than morphine, is said to be less constipating, and has advantages for patients with hepatic or renal failure. It is available as an immediate-release oral form or parenterally.

A really useful table is the conversion table in *Therapeutic Guidelines Palliative Care*, p 105, pp 107 - 116. This table shows the opioids available in Australia, compared in terms of their strength relative to morphine. You don't need to memorise this table, but you do need to know where to look for the information!

Oral delivery of medications is the best choice. Consider under what circumstances other modes of administration might be considered.



Readings

Read the chapter entitled Getting to Know your Drugs, *Therapeutic Guidelines Palliative Care*, pp 95 - 138.

This is a useful reference chapter with comprehensive notes on virtually all the medications used in pain management. Again, know where to look for detailed information rather than memorise all of this.



Activity 15

During your clinical placement, discuss the various alternatives for managing the different pain types / mechanisms.

Consider when you would prescribe an opioid and in what circumstances would the addition of a non-opioid be necessary.

3.9 Assessing and managing nausea and vomiting



Readings

Read the section on Nausea and Vomiting, *Therapeutic Guidelines Palliative Care*, pp 238 - 246.

Nausea and vomiting are common, distressing and demand instant attention. Treatment to alleviate this distressing condition needs to be started immediately. Nausea is the final common pathway for a considerable range of problems. In the same way as pain has to be assessed in order to be treated rationally, so nausea needs a rational assessment. The key diagram that assists in this assessment process is Figure 2 *Therapeutic Guidelines Palliative Care*, p 239.

In refractory nausea, it is possible to use multiple anti-emetic agents, added sequentially. Choose agents that target different points of the vomiting pathway.

Much work is currently underway in Australia to understand the predictors of nausea, and to develop evidence-based algorithms for the assessment and management of nausea.

Extra Reading

Glare P, Pereira G, Kristjanson LJ, Stockler M, Tattersall M. Systematic review of the efficacy of antiemetics in the treatment of nausea in patients with far-advanced cancer. Supportive Care in Cancer 2004;12(6):432-40.

3.10 Assessing and managing constipation



Before completing this section, read the section on constipation and bowel obstruction *Therapeutic Guidelines Palliative Care*, pp 246 - 257.

Constipation is almost inevitable in very ill people, due to the combination of poor fluid and fibre intake, reduced peristalsis, reduced abdominal muscle tone and, at times, lack of privacy. In addition, many of the drugs that are used in palliative care reduce gut peristalsis, particularly opioids and drugs with anticholinergic modes of action. It is essential that the potential for constipation is considered and steps are taken to prevent it. Treating established constipation is very distressing for debilitated patients.

Bear in mind that the major problems are hard stools, and reduced peristalsis. The laxatives you select need to counter these problems. The most commonly used laxatives in the community are bulking agents. However, bulking agents rely on adequate fluid intake to produce bulky stools, and assume normal peristalsis to propel them forward. Most palliative care patients have poor fluid intake and reduced gut motility. This can lead to hard stools that are very difficult to pass. It is therefore not advisable to use bulking agents in the palliative care setting. Most patients do better with agents that are combinations of a faecal softener and a stimulant laxative, such as docusate (coloxyl) 50 mg and senna 8 mg tablets. Some patients need significant doses - up to 3 tabs tds.

3.11 Assessing and managing confusion



Before completing this section, read the section on cognitive failure in *Therapeutic Guidelines Palliative Care*, pp 290 - 293.

The key issue here is to be aware of reversible causes of confusion. It may be possible to prevent delirium by minimising risk factors, such as reducing or ceasing drugs with an anticholinergic action. Some authorities believe that regular monitoring of cognitive function is warranted to identify the onset of confusion and delirium early.

Instruments to assist in the assessment of confusion can be found at:

Mini Mental State examination: Yellowlees P. Psychiatric assessment in community practice. Medical Journal of Australia, 1997, Aug 4;167(3):149-56.

<http://www.mja.com.au/public/mentalhealth/articles/yellowlees/yellowlees.html>

Delirium Rating Scale

Trzepacz P, Baker R, Greenhouse J. A symptom rating scale for delirium. Psychiatry Research, 1988, 23: 89-97.

3.12 Assessing and managing anorexia, cachexia, lethargy and fatigue

These symptoms are extremely common in cancer. They are symptoms that are the most obvious manifestations of the advancement of the disease, and cause considerable distress to patients and their carers. At this time, there is little to be done to reverse their progress. Some agents can improve appetite temporarily (eg high dose provera, dexamethasone). Cachexia is not helped by eating more. Moreover, appetite and taste perception changes, and the patient may reject foods that were previously favourites. Since providing pleasant food is one of the few things carers can actively contribute to care, this is quite upsetting for them. However, much can be done in terms of how food is presented, and what to tell patients and relatives. You may wish to contact a dietician to advise your patient and carer.

Lethargy is extremely difficult to reverse medically, and is a universal symptom of advanced disease regardless of the cause. The stimulant medications dexamphetamine and methylphenidate can be useful here, but these do need to be considered with caution as these medications can cause psychosis.

Assess that the observed reduced activity is really lethargy and not clinical depression.



For more information, read *Therapeutic Guidelines Palliative Care*, pp 229 – 230, 235 – 238.

3.13 Administering drugs to people who can't swallow.

There are alternative routes available to people who cannot swallow medications. Some patients may have a PEG tube through which oral medications can be administered. Other routes include transdermal, parenteral (subcutaneous or I/V), buccal and rectal. For regular medication delivery, transdermal and subcutaneous routes are most commonly used.

When converting from oral to either of these routes, the following considerations have to be made:

- Can I use the same drug in a different form, or do I have to convert from one drug to another?
- What is the bioequivalence of the same medication by different routes?
- Will the symptom be adequately controlled in the change over period? Will I need break-through medication or a tapering dose of the oral form?
- Will there be support to the patient in case problems arise with the new route of medication?

Syringe drivers and pumps can be used to deliver more than one medication. Watch out for incompatible treatments. Useful tables and information are found in Appendix 1, *Therapeutic Guidelines Palliative Care*, pp 366 – 370 or via QLD CPCRE web site at www.cpcpre.com

Click on Syringe Driver Education



Activity 16

Take time to talk to and watch the palliative care staff setting up and using a syringe driver. If one of your patients required administration of medications via a syringe driver in the community, how would you access one of these pumps?

3.14 Responding to difficult palliative care situations

3.14.1 Fluids, feeding and oxygen

This is one of the most difficult issues facing patients, their families and health care staff.

Perennial problems arise in trying to assess the usefulness of artificial feeding and hydration. Do patients suffer hunger and thirst, or are the problems really anorexia and dry mouth? What are the consequences for a patient of supplying parenteral nutrition, or using a feeding tube? Do they improve quality of life for the patient, or simply make the carers feel better because 'something is being done'?

The same is true of oxygen supplementation. There is little relationship between the sense of breathlessness and hypoxia. For some, the supply of oxygen will make a world of difference, for others it will be of psychological benefit only. Once oxygen is supplied it is very difficult to withdraw it. Other interventions can assist some patients in the management of breathlessness such as:

- the use of fans to cause some movement of air;
- reassurance; and / or
- the prescribed use of anxiolytics

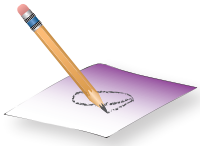
3.14.2 Referral to Specialist Services

Despite the majority of palliative patients being able to be supported prior to their death by generalist health professionals including general practitioners and community nurses, some will require management by specialist palliative care services. To aid in determining a more transparent and objective mechanism for the decision about who accesses (or does not need to access) specialist services the following tool has been developed: *Palliative Care Needs Assessment Guidelines & Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C)*. This tool has been developed by the University of Newcastle and can assist in matching the types and levels of need experienced by people with advanced cancer and their caregivers with the most appropriate people or services to address those needs. A summary version of the Guidelines and a copy of the NAT: PD-C are available at <http://www.caresearch.com.au/caresearch/WhatIsPalliativeCare/NationalPalliativeCareProgram/PalliativeCareNeedsAssessmentFramework/tabid/100/Default.aspx>

3.14.3 The patient who wants help to die

In all Australian States and Territories, euthanasia remains illegal. However, there is evidence that some people would contemplate this action ⁽⁸⁾ and that doctors do take deliberate steps to shorten the lives of patients.⁽⁹⁾ Some treatment decisions may have the unintended consequence of potentially shortening life, although the intention of the action is to relieve the suffering of the patient.

Many patients asking for assistance to die are seeking help with the situation they are in and the management of difficult issues. Patients who make a request for assistance to die may be depressed. Of the seven patients who had legally sanctioned euthanasia in the Northern Territory, five were found to be depressed on independent review of the records ⁽¹⁰⁾. They may also have symptoms that are not optimally controlled. For both of these reasons, adequate treatment may remove the motivation to seek deliberate ending of life. However, the main reason for stated intent to choose to end life is loss of control and loss of dignity through needing to rely on other people for daily nursing.



Activity 17

Think about...

How would you respond to a request to shorten life?

Should a treatment you administered to alleviate a symptom potentially shorten life, would this change your intended action? Why/Why not?

Extra reading:

Hunt RW. Taking responsibility for affecting the time of death. Palliative Medicine, 1999; 13: 365-6.

Gilbert J, Kirkham S. Double effect, double bind or double speak? Palliative Medicine, 1999; 13:365-366

3.14.4 When does palliative care end?

Palliative care does not end when the patient dies. The family or carers undertake an enormous burden when they care for a patient. Frequently they leave their life on hold for months, even to the point of resigning from their job. After the death of the patient, the caregiver, family members and friends go through a process of working out how to live life in the absence of a loved individual. Grieving can take many months to years and is a process that integrates the death of the patient into their life. Surviving care-givers are never the same as before.

For a small number, the grief process may not progress and some people can develop major psychological consequences. It is essential that the surviving carers are followed to ensure that these problems are identified early and referred for expert care if required.

Another reason for follow-up of bereaved relatives is that all-cause morbidity and mortality rates increase in the twelve months after the death of a spouse.

Bereaved relatives or carers expect some form of contact from the treating doctor, and appreciate it when it comes ⁽¹¹⁾.



Readings

Read *Therapeutic Guidelines Palliative Care*, pp 42 - 57 for more information on this important topic.



Activity 18

Think about...

Do I have a strategy to keep in contact with the surviving carers of my patients where the carers may be at risk of complicated bereavement?

Are there bereavement support services in my area where I may refer family members?

3.14.5 Keeping up in palliative care

As a young discipline, palliative medicine's knowledge base is expanding rapidly. As a GP who sees a few deaths a year, it will be difficult to keep abreast of the changes. Try to have access to a current handbook as a baseline reference. The web pages noted below have up to date information on palliative care treatments. Of most use will be what you learn when working with your specialist team. We would hope that following your placement, you will be comfortable to consult with specialist palliative care providers. Consider making a habit of discussing current cases with them. Take the opportunity to participate in case conferences with them – perhaps even consider setting one up if you feel you and your patient may benefit. This is a two way street as the specialists benefit from your contextual knowledge of the patient, while you learn of new treatments in the context of your patient.

4 Clinical Exercises

If your learning objectives are clear, they should occupy much of your time at the palliative care service(s). If you have time, or your learning objectives don't cover these issues, see if you can have a go at these clinical exercises.

4.1 The patient's perspective.

While not neglecting the presenting symptoms, talk to the patients about how they were referred to the palliative care service/ unit.

What was it like to be referred to a palliative care team?

What made this event easy and what made it difficult?

What actions of the palliative care team would have made the referral easier?

4.2 Load a syringe driver yourself.

Set the syringe driver's delivery rate, and set it up on a patient.

4.3 Using the opioid conversion table.

Use the table on *Therapeutic Guidelines Palliative Care*, p 105, pp 107 - 116 to practice converting oral doses of medication to doses for the syringe driver.

Use the table to convert one form of opioid to another – eg

- Oral Morphine to Sub-cutaneous morphine
- Oral morphine to Fentanyl patches
- Paracetamol & Codeine 500 / 30 mg (Panadeine forte) to oral morphine

Practice your conversions on the following page.

| Existing drug and route | Existing drug dose | New drug | Conversion rate | New drug dose |
|---------------------------|---|---------------------------------|---------------------------|--|
| MS Contin po Ordine po | 60mg bd 10mg q2h prn 6 doses required daily (Total oral dose over 24 hours = 180 mg) | Morphine sulphate for injection | Oral: Parenteral 3 : 1 | 60 mg Morphine S/C delivered over 24 hours via a syringe driver For breakthrough pain: 1/12 of 24 hour oral dose = 15mg Ordine po q2h prn OR 1/12 of 24 hour S/C dose = 5 mg Morphine S/C q2h prn |
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4.4 Assessment of a patient's pain

Use some of the pain assessment tools. For example, visual analogue scales and body charts (*Therapeutic Guidelines Palliative Care*, pp 371 - 374) can assist in making a more accurate assessment of the locations and type of pain the patient has.

Questions to ask

- Is the patient experiencing different types of pain? Can you categorise the pain/s? This will help direct pain management.
- What medication types could be employed to alleviate this (these) pain(s)?

4.5 Undertake a medical assessment of a patient

Take a comprehensive history from a patient. Construct an issue list and potential management plans. Try to prioritise the problems the patient presents with. Don't forget to include non-medical issues the patient may present with. Briefly outline potential management strategies and which team members can contribute to the care of the patient.

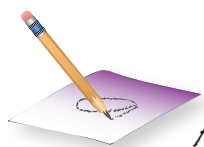
| Issue No. | Description | Diagnosis | Priority number | Outline of management |
|-----------|-------------|-----------|-----------------|-----------------------|
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4.6 List the members of the host team (including community palliative care team)

| Name | Job Title | Role | Contact Details |
|------|-----------|------|-----------------|
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5 Applying Your Learning

The aim of PEPA is to enhance the capacity of local communities to provide a palliative approach, by enhancing the knowledge, skills and experience of primary health staff. So of course, your learning and experience should be used in your own workplace.



Activity 19

Reread your preparatory Activities 1 – 5. What did you identify as the main issues for a patient with life-limiting illness and their families in your practice / workplace? Have you identified activities that you can implement to improve outcomes for this group of patients? Discuss these activities and other strategies with your palliative care mentor.

Consider other opportunities to share your PEPA experience, and your enhanced knowledge and skills with your colleagues and team. These may include:

- Presenting at a general practice / workplace meeting;
- Writing an article for the local division newsletter / journal;
- Having provision of palliative care in the GP division included on the agenda of the local meeting;
- Inviting the local palliative care providers (including members of the multidisciplinary team) to present at a meeting;
- Presenting a palliative care article at a journal club;
- Discussing the burning issues at your practice/ workplace with colleagues;
- Presenting your workplace quality activity at a meeting, discussing the evaluation of the activity, patient and family outcomes and opportunities for further improvement.

Why not make an appointment with your mentor five to six weeks after your placement to discuss your workplace activity? This could be put in your diaries and a phone contact made to touch base and talk through your achievements, challenges and other strategies.

6 Palliative Care Resources

6.1 Websites

6.1.1 General resources

Palliative Care Australia

www.palliativecare.org.au

National organisation for palliative care. This site has contact details for all state organisations and several research and policy documents

Australian Government Department of Health and Ageing – National Palliative Care Program

<http://www.health.gov.au/palliativecare>

Describes the Australian Government's commitment to palliative care, national guidelines for palliative care in specific settings, publications available online and extensive weblinks to national and international websites

Caresearch

www.caresearch.com.au

A national database of research resources in palliative care, including an anthology of grey literature in palliative care, search strategies to identify palliative care topics in common databases, and a researcher's section which may be used for multi-site collaborations.

Current Learning in Palliative Care

www.helpthehospices.org.uk

This British website offers more than fifty 15 minute modules/worksheets providing an excellent overview of key topics in palliative care (enter the search term 'CLiP' for e-learning tutorials).

6.1.2. Websites with clinical information

International Association for Hospice Care

<http://www.hospicecare.com/resources/pain-research.htm>

A comprehensive anthology of written assessments for clinical problems in palliative care.

Palliative drugs information

www.Palliatiivedrugs.com

Comprehensive listings of drugs, side effects and therapeutic guidelines.

Centre for Palliative Care Research and Education

www.cpcrc.com

Has good resources around the delivery of evidence based palliative care. Additionally has links to the content pages of palliative care- specific journals.

6.2 Textbooks

Therapeutic Guidelines: Palliative Care Version 3, 2010. Melbourne. Also available in electronic formats for desktop computers and handheld devices at <http://www.tg.org.au/>

Woodruff, R. Palliative Medicine: evidence-based symptomatic and supportive care for patients with advanced cancer. Melbourne: Oxford University Press, 2004.

Doyle D, Hanks G., MacDonald N. Oxford Textbook of Palliative Medicine. Third Edition Oxford. OUP, 2004.

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4. National Breast Cancer Centre and the National Cancer Control Initiative. Clinical practice guidelines for the psychosocial care of adults with cancer. Australia: NHMRC; 2003.
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11. Harris T, Kendrick T. Bereavement care in general practice: a survey in South Thames Health Region. British Journal of General Practice 1998;46:1560-1564.



Therapeutic Guidelines: Palliative Care Version 3, 2010. Melbourne. Also available in electronic formats for desktop computers and handheld devices at <http://www.tg.org.au/>

Glare P, Pereira G, Kristjanson LJ, Stockler M, Tattersall M. Systematic review of the efficacy of antiemetics in the treatment of nausea in patients with far-advanced cancer. Support Care Cancer 2004;12(6):432-40.

Appendix 1

Definition of Terms from Palliative Care Australia's Palliative and End of Life Care Glossary of Terms Edition 1, 2008

Palliative approach

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

Life-limiting illness or condition

Not recommended. Terminal condition or eventually fatal condition preferred.

Eventually fatal condition

A progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant illness and ageing.

A person has an eventually fatal condition if their death in the foreseeable future would not be a surprise.

The terms eventually fatal or terminal condition are used interchangeably. In reference to the patient: language that refers to 'living with an eventually fatal (or terminal) condition' is recommended.

Patient

A patient is the primary recipient of care.

In the practice of palliative care the patient, together with their family and carers are the focus of care.

Primary carer

The primary carer is generally in the close kin network of the patient and is usually self identified. The primary carer can be the patient's spouse, child, another relative, family member or friend. They may be supported by other carers, but generally will take a primary role in the co-ordination and delivery of care and support to the patient. This person provides for the practical needs of the patient and takes on additional tasks that may be of a technical nature, to provide ongoing care for the patient, e.g. the administration of medications. They provide the primary support role for the patient at all levels of need.

Appendix 2

Palliative Care Australia's Standards for Providing Quality Palliative Care for all Australians (Fourth Edition, 2005)

Standard 1

Care, decision-making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patient, their caregiver's and family's needs and wishes are acknowledged and guide decision-making and care planning.

Standard 2

The holistic needs of the patient, their caregiver/s and family, are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.

Standard 3

Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.

Standard 4

Care is coordinated to minimise the burden on patient, their caregiver/s and family.

Standard 5

The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes.

Standard 6

The unique needs of dying patients are considered, their comfort maximized and their dignity preserved.

Standard 7

The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.

Standard 8

Formal mechanisms are in place to ensure that the patient, their caregiver/s and

family have access to bereavement care, information and support services.

Standard 9

Community capacity to respond to the needs of people who have a life limiting illness, their caregiver/s and family is built through effective collaboration and partnerships.

Standard 10

Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.

Standard 11

The service is committed to quality improvement and research in clinical and management practices.

Standard 12

Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

Standard 13

Staff and volunteers reflect on practice and initiate and maintain effective selfcare strategies.