

Chapter 12

End-of-life care

LEARNING OBJECTIVES

On completion of this chapter, the learner should be able to:

1. Discuss the historical, legal and sociocultural perspectives of palliative and end-of-life care in Australia and New Zealand.
2. Define palliative care.
3. Compare and contrast the settings where palliative care and end-of-life care are provided.
4. Describe the principles and components of palliative care.
5. Identify barriers to improving care at the end of life.
6. Reflect on personal experience with and attitudes towards death and dying.
7. Apply skills for communicating with terminally ill patients and their families.
8. Provide culturally and spiritually sensitive care to terminally ill patients and their families.
9. Implement nursing measures to manage physiological responses to terminal illness.
10. Support actively dying patients and their families.
11. Identify components of uncomplicated grief and mourning and implement nursing measures to support patients and families.

KEY TERMS

assisted suicide	life-limiting illness
autonomy	mourning
bereavement	palliative care
euthanasia	prognosis
grief	sedation
hospice	spirituality
interdisciplinary collaboration	

Alleviation of pain and suffering is a fundamental nursing responsibility, and nurses are uniquely prepared to offer quality care for dying patients and their families. Nurses are educated in pain management, palliative care and in helping people cope with grief, death and dying.

Knowledge about end-of-life decisions and principles of care are essential to supporting patients and their families during decision making and in end-of-life closure in ways that

recognise their unique responses to illness and support their values and goals. Education, clinical practice and research concerning end-of-life care are evolving, and the need to prepare nurses and other healthcare professionals to care for the dying has emerged as a priority (Australian Department of Health and Ageing [ADHA], 2015). At no time in nursing's history has there been a greater opportunity to bring research, education and practice together to change the culture of dying, bringing much-needed improvement to care that is relevant across practice settings, age groups, cultural backgrounds and illnesses.

The terminology used surrounding care of people who have a life-limiting illness may at first appear very confusing. Many of the terms used have changed over time, are poorly defined or can be interpreted differently, depending on factors such as culture or location (ADHA, 2015; Australian Institute of Health and Welfare [AIHW], 2014; Gysels et al., 2013; Hui et al., 2013). It is, therefore, necessary to provide definitions as they are used throughout this chapter. A life-limiting illness refers to an illness/condition which may eventually lead to a person's death whether it is years, months, weeks or days away (New Zealand Ministry of Health (NZMOH), 2015a; Palliative Care Nurses New Zealand (PCNNZ), 2014). End-of-life care describes the last days when a person is irreversibly dying (Gysels et al., 2013; Hui et al., 2013). Caring for dying patients is a role that most nurses will encounter regardless of where they practice. End-of-life care is an important aspect of palliative care; however, patients with a life-limiting illness may live for many years. Palliative care may be appropriate early in the course of an illness and be provided alongside curative treatments (Naeim et al., 2014). Not all patients who have a life-limiting illness will require specialist palliative care services; however, all patients and their family members deserve compassionate and competent care at the end of life.

The term **palliative care** is used throughout this chapter to describe the care provided to people with life-limiting illness by nurses and other healthcare professionals in Australia and New Zealand. This term is also known in New Zealand as 'hospice palliative care'. The term hospice is used in this chapter to describe the place where specially trained doctors, nurses and others provide palliative care for people who are dying. Palliative nursing is now accepted as an area of specialty practice in Australia, with its own advanced practice competencies and a professional organisation, Palliative Care Nurses Australia (PCNA). In Aotearoa New Zealand, a national framework for palliative care nursing has been developed which includes competencies in Aotearoa New Zealand (Palliative Care Nurses New Zealand, 2014). These organisations are committed to leading and facilitating

knowledge, research, education and policy in palliative care for providers and patients.

Nursing and end-of-life care

Context for death and dying

Technological advances, public health initiatives, health education and pharmacological breakthroughs have contributed to improved life expectancies for people, particularly in developed countries. These factors have had an impact on policy direction for access to palliative care services through initiatives such as the National Palliative Care Strategy (ADHA, 2010), supported by substantial funding through the Australian Health Care Agreement. In Australia and New Zealand, standards have been developed to support and enhance quality of care for patients who are at the end of their life, their families and carers (Hospice New Zealand, 2012; Palliative Care Australia [PCA], 2005a). These standards reflect the World Health Organization (WHO) (2016) statement as cited below.

‘Palliative care

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor to postpone death;
- integrates psychological and spiritual aspects of patient care;
- offers a support system to help patients to live as actively as possible until death;
- offers a support system to help the family to 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.’

Palliative care standards have been developed in Australia and New Zealand in order to provide consistent and quality palliative care (Hospice New Zealand, 2012; PCA, 2005a) The palliative care standards were developed in consultation with both professional groups and the community engaged in delivering and using palliative care. The palliative care standards provide a broad framework for service delivery which is applicable in all care settings. The palliative care standards acknowledge the rights and needs of patients and their families to not only receive support and services but also guide care planning and decision making (Hospice New Zealand, 2012; PCA, 2005a). A voluntary quality program, the Palliative Care Outcomes Collaboration (PCOC) (2015), supports quality improvement and benchmarking for palliative care service providers using the PCA (2005a) standards as a framework.

Palliative Care Outcomes Collaboration provides facilitators, staff training, validated data sets, help with data collection and reporting and a benchmarking service to palliative care providers. There are four outcome measures used to benchmark services.

- *Outcome measure 1* directly measures the time from referral of a patient or client to a palliative care service and the first contact made with them. In 90% of referrals, contact is made within a day of the referral.
- *Outcome measure 2* focuses on unstable phases of palliative care with differing benchmarks assigned to stabilising management at different phases of the palliative care episode.
- *Outcome measure 3* targets pain management at different phases of palliative care episodes as measured by validated pain assessment scales.
- *Outcome measure 4* monitors successful symptom management against a baseline national average for ‘like’ patients (PCOC, 2015).

Many organisations have used these standards and principles to develop clinical guidelines for quality palliative and end-of-life programs.

Technology and end-of-life care

In the last century, chronic, degenerative diseases replaced communicable diseases as the major causes of death. In the earlier part of the 20th century, most deaths occurred at home. Most families had direct experience with death, providing care to family members at the end of life and then mourning their losses. As the place of death shifted from home to hospitals, families became increasingly distanced from the death experience.

Although technological advances in healthcare have extended and improved the quality of life for many, the ability of technologies to prolong life beyond the point that some would consider meaningful has raised troubling ethical issues. In particular, the use of technology to sustain life has raised perplexing issues with regard to quality of life, prolongation of dying, adequacy of pain relief and symptom management and allocation of scarce resources. It also has an effect on how clinicians care for the dying, how family and friends participate in care, how patients and families understand and choose end-of-life care options, how families prepare for **life-limiting illness** and death and how they heal after the death of a loved one.

Sociocultural context

Although each individual experiences life-limiting illness uniquely, such illness is also shaped substantially by the social and cultural contexts in which it occurs. In Australia and New Zealand, life-limiting illnesses, end-of-life treatment decisions, dying and death occur in a social environment where illness is generally considered a foe and patients are encouraged to ‘fight the disease’. Although a receptive attitude

towards palliative care services is growing among healthcare professionals who recognise the value of supportive care and expert symptom management available through palliative care programs, there is still a reluctance to abandon a cure-oriented approach to care. In such a model of health or medical care, alleviating suffering is not as valued as curing disease, and patients who cannot be cured feel distanced from the healthcare team, concluding that when treatment has failed, they too have failed. Patients and families who have internalised the socially constructed meaning of care as 'second best' may fear that any shift from curative goals in the direction of comfort-focused care will result in no care or poorer-quality care.

Strategies such as earlier introduction of palliative care services in the disease trajectory for people with life-limiting illness have proved useful in reducing the cure/care divide. In palliative care, perhaps more than any other area, quality of life is a better outcome measure of good nursing care than eradication of disease. Such measures reflect the WHO guidelines for palliative care provision previously discussed.

Clinicians' attitudes towards death

Clinicians' attitudes towards dying remain the greatest barrier to improving care at the end of life. Kübler-Ross illuminated the concerns of the seriously ill and dying in her seminal work, *On Death and Dying*, in 1969. At that time, it was common for patients to be kept uninformed about life-threatening diagnoses, particularly cancer, and for doctors and nurses to avoid open discussion of death and dying with their patients. The work by Kübler-Ross revealed that given open discussion, adequate time and some help in working through the process, patients could reach a stage of acceptance in which they were neither angry nor depressed about their fate (see later discussion).

Clinicians' reluctance to discuss disease and death openly with patients stems from their own anxieties about death as well as misconceptions about what and how much patients want to know about their illnesses. In an early study of care of the dying in hospital settings, sociologists Glaser and Strauss (1965) discovered that healthcare professionals in hospital settings avoided direct communication about dying in hope that the patient would discover it on his or her own. They identified four 'awareness contexts':

1. *Closed awareness*: The patient is unaware of his or her terminal state, whereas others are aware. Closed awareness may be characterised as a conspiracy between the family and the healthcare professionals to guard the 'secret', fearing that the patient may not be able to cope with full disclosure about his or her status, and the patient's acceptance of others' accounts of his or her 'future biography' as long as the others give him or her no reason to be suspicious.
2. *Suspected awareness*: The patient suspects what others know and attempts to find out details about his or her condition. Suspected awareness may be triggered by inconsistencies in the family's and the clinician's communication and behaviour, discrepancies between clinicians' accounts of the seriousness of the patient's illness or a

decline in the patient's condition or other environmental cues.

3. *Mutual pretense awareness*: The patient, the family and the healthcare professionals are aware that the patient is dying, but all pretend otherwise.
4. *Open awareness*: The patient, the family and the healthcare professionals are aware that the patient is dying and openly acknowledge that reality.

Glaser and Strauss (1965) also identified a pattern of clinician behaviour in which those clinicians who feared or were uncomfortable discussing death developed and substituted 'personal mythologies' for appraisals of what level of disclosure their patients actually wanted. For example, clinicians avoided direct communication with patients about the seriousness of their illness based on their beliefs that (1) patients already knew the truth or would ask whether they wanted to know, or (2) patients would subsequently lose all hope, give up or be psychologically harmed by disclosure.

Although Glaser and Strauss's findings were published decades ago, their observations remain valid today. The growth of palliative and hospice care programs has led to greater numbers of healthcare providers becoming comfortable with assessing patients' and families' information needs and disclosing honest information about the seriousness of illness (Ferrell & Coyle, 2010). However, in many settings, clinicians still avoid the topic of death in hope that patients will ask or find out on their own. Despite progress on many healthcare fronts, many who work with seriously ill and dying patients recognise a persistent conspiracy of silence about dying.

How to communicate truthfully with patients and encourage patient autonomy in a way that acknowledges where they are on the continuum of acceptance remains a challenge. Despite continued reluctance of healthcare providers to engage in open discussion about end-of-life issues, it has been confirmed that patients want information about their illness and end-of-life choices and that they are not harmed by open discussion about death (American Nurses Association [ANA], 2010; Barclay et al., 2011). Timing of sensitive discussion takes experience, but speaking the truth can be a relief to patients and families, enhancing their autonomy by making way for truly informed consent as the basis for decision making.

Patient and family denial

Contemplating mortality is usually a source of discomfort for most people, and Western culture is generally accepted as death denying (Zimmermann, 2007, 2012). The way people die has changed over time. Technology, early diagnosis and medical advancements have prolonged the dying process in comparison to the past. Previously, death most often occurred at home, with little medical intervention, and the need to plan for or make decisions was not required (Zimmermann, 2012). The need for openness in preparing for death is now considered as best practice (Noble et al., 2015); however, denial may be an effective coping mechanism. It is important for nurses not to use the term denial in a judgmental way as

this may imply that there is a correct way to die (Zimmermann, 2007, 2012). Denial may become a barrier to care if patients or families refuse to acknowledge a diagnosis or refuse to hear about treatment options (Noble et al., 2015). Nurses must accept patients regardless of the degree to which they are in denial about their illness and work with other healthcare providers to present a consistent message.

Patient and family awareness of **prognosis** is a key factor in acceptance of and planning for death. Even patients and families who have received clear and honest information may not fully accept the situation. For patients who have been informed about life-limiting illness, their understanding of treatment goals and prognosis is dynamic and may sometimes require reinforcement. Another concern is that patients' and their caregivers' understanding of treatment goals and prognosis can differ dramatically. In a study of patients receiving palliative radiation therapy for cancer metastases, researchers found that 25% of patients believed that their cancer was curable, and there was no change before and after therapy in belief that radiation therapy would cure the cancer and prolong their lives (Mitera et al., 2012).

Such misunderstandings can complicate both delivery of effective care and informed consent for care. Patients with non-cancer diagnoses, such as heart failure, chronic obstructive pulmonary disease (COPD), kidney failure, dementia or neurodegenerative diseases, such as amyotrophic lateral sclerosis, frequently do not receive adequate information and support to fully understand their prognosis, yet they often desire clear and honest information. For example, they may have troublesome symptoms and reduced quality of life paralleling or exceeding that of those patients with cancer. Patients may want, but are unlikely to receive, clear information about disease progression, advanced care planning and prognosis. Similarly, in a qualitative study of preferences for prognosis communication among patients with end-stage heart failure, researchers found a strong preference for doctor disclosure about treatment possibilities and probable outcomes (i.e. a balance of honest disclosure with hope) (Barclay et al., 2011). Clearly, further research is needed to examine the complex interactions between patients' misconceptions about advanced illness, their underlying psychological states and clinicians' persistent lack of explanations of treatment expectations and prognosis.

The question of how to communicate with patients in a way that acknowledges where they are on the continuum of acceptance, while providing them with unambiguous information, remains a challenge. Although timing of the questions takes experience, speaking the truth can be a relief to patients and families, enhancing their **autonomy** by making way for truly informed consent as the basis for decision making.

Euthanasia and assisted suicide

The euthanasia and assisted suicide debate has highlighted the adequacy and quality of end-of-life care in Australia and New Zealand. **Euthanasia** is the intentional ending of life and may be voluntary or involuntary. **Assisted suicide** refers to providing another person with the means to end his or her

own life. Doctor-assisted suicide involves the prescription by a doctor of a lethal dose of medication for the purpose of ending someone's life (not to be confused with the ethically and legally supported practices of withholding or withdrawing medical treatment in accordance with the wishes of the person with a life-limiting illness).

Judeo-Christian beliefs support the view that suicide is a violation of natural law and the law of God. However, there have recently been calls for the legalisation of euthanasia and assisted suicide. Although the preference to take one's own life over awaiting death has been evident through the ages, these recent efforts to legalise euthanasia and assisted suicide underscore the need for changes in the ways individuals with life-limiting illnesses are cared for and treated at the end of their lives. This is further emphasised by the growth of voluntary euthanasia groups in Australia and New Zealand, which lobby doctors and governments to adopt doctor-assisted suicide laws. One such group, Exit International, publishes information and conducts workshops across Australia and New Zealand for people looking for advice on how to end their lives.

In Australia, an adult of sound mind has the right to refuse treatment but not to request assistance to terminate his or her life. Concepts such as autonomy and self-determination have been used to challenge the law prohibiting actions which might be confused with euthanasia in countries where euthanasia has not been legalised (Griffith, 2007; White & Willmott, 2012). Although assisted suicide is expressly prohibited under statutory and common law in Australia and New Zealand, calls for legislative reform have highlighted many inadequacies in the care of the dying and the ethical and legal dilemmas faced by healthcare professionals. Johnstone (2014) states that nurses in Australia 'have been under immense pressure by pro euthanasia supporters to take a definitive stance advocating the legalisation of euthanasia' (p. 32). Nurses have a responsibility to be well informed regarding complex moral issues rather than merely succumbing to media influence (Johnstone, 2014). Surveys of healthcare professionals in Australia, New Zealand and overseas now consistently show that a considerable proportion of them support euthanasia or doctor-assisted suicide under certain conditions. A survey of community attitudes showed increasing support for euthanasia (79%) and doctor-assisted suicide (69%) among cancer sufferers and endorsed these options for themselves (68%). However, very few people had actually acted upon these beliefs as only a few (5%) had actually enquired about euthanasia or doctor-assisted suicide (Carter et al., 2007). Similarly, Sikora and Lewins (2007) found that more Australians supported voluntary euthanasia than opposed it.

In Australia, the Northern Territory passed the Rights of the Terminally Ill Act (endorsing voluntary euthanasia/assisted suicide) in 1995, the first legislation of its kind in the country. The medical certificates required by the Act proved difficult to obtain in the face of hostility from the Australian Medical Association and intense public scrutiny through the media. Four patients were helped to die under the terms of

the Act before it was revoked by the Australian Federal Parliament in 1997. On 24 June 2014, an exposure draft of the Medical Services (Dying with Dignity) Bill 2014 was referred to the Senate Legal and Constitutional Affairs Legislation Committee for inquiry and report (Parliament of Australia, 2014). The Senate requested that in reviewing the Bill the committee consider the rights of dying people to seek assistance in ending their lives and the frameworks and safeguards that would be needed. The inquiry resulted in a large number of submissions from individuals and organisations, which are accessible online; however, to date, the Bill has not been taken any further (Parliament of Australia, 2014).

Voluntary euthanasia remains illegal in New Zealand and the opinions of New Zealanders remain divided over this issue. A case in New Zealand that attracted attention all around the world involved Lecretia Seales (Geddis, 2015). Seales was a 42-year-old lawyer in Wellington, New Zealand, and was diagnosed with an inoperable brain tumour. Seales took her case to the High Court in New Zealand and was seeking the right to die with assistance from her general practitioner (GP). Although taking her own life was not illegal in New Zealand, Seales wanted to ensure that her GP would not be convicted of murder, manslaughter or aiding suicide, under the Crimes Act (1961), by helping her to die. In his notes, Justice Collins states that 'Although Ms Seales has not obtained the outcomes she sought, she has selflessly provided a forum to clarify important aspects of New Zealand law (Seales v Attorney General, 2015, p. 162)'. Seales died of natural causes the day prior to the court decision being publicly released (Geddis, 2015).

Proponents of doctor-assisted suicide argue that people who have a life-limiting illness should have a legally sanctioned right to make independent decisions about the value of their lives and the timing and circumstances of their deaths. Its

opponents argue for greater access to symptom management and psychosocial support to ensure that the terminally ill have the right not to suffer. Numerous ethical and legal issues have arisen including voluntariness; authenticity of the request in relation to the mental competence and decision-making capacity of people seeking doctor-assisted suicide; the existence of underlying untreated clinical depression; and issues of overt or perceived coercion (see Chart 12-1).

Assisted suicide is opposed by nursing and medical organisations as a violation of the ethical traditions of nursing and medicine. The New Zealand Nurses Organisation (NZNO), PCA, Hospice New Zealand and the Australian and New Zealand Society of Palliative Medicine (ANZSPM) believe that if more people had access to quality hospice and palliative care, fewer people would persistently seek euthanasia or assisted suicide. The ANZSPM's Position statements on the Practice of Euthanasia and Assisted Suicide acknowledge the complexity of the voluntary euthanasia/assisted suicide debate; however, they clearly oppose any nursing or medical participation in such acts. The ANZSPM (2013) stresses that nurses and doctors have a primary responsibility to provide quality care to dying patients and their significant others. For many, the euthanasia debate may be seen as diverting attention and resources from palliative care thereby risking erosion of services. White and Willmott (2012) acknowledge the extraordinary complexities of the debate and urge proponents on both sides to abandon 'sloganism and rhetoric' which serve to inhibit rational engagement with the core legal and ethical principles underlying the issue.

Palliative care settings for end-of-life care

Palliative care is an approach to care for the seriously ill that has long been a part of cancer care. The WHO (2016) defines

CHART 12-1 ETHICS AND RELATED ISSUES

What if patients ask you to help them to end their life?

Situation

You are a hospice nurse visiting a 72-year-old man with prostate cancer and metastasis to the bone. He reports severe pain that is increasing and unrelieved by any of the pharmacological and non-pharmacological interventions that have been tried. He lives with his wife but has no other family members nearby or close friends. He has told his only surviving son, who lives across the country, that he wants to obtain assistance to help him die when the pain becomes unbearable. He asks whether you can help him with this request.

Dilemma

Assisted suicide remains a highly controversial topic—is it a matter of personal choice (i.e. does it preserve the autonomy of those who are dying), or does it constitute homicide by healthcare professionals who should 'first do no harm' (i.e. non-maleficence)?

Discussion

1. What should your follow-up consist of?
2. Should you discuss the patient's request with his wife before you end the visit that day? Discuss the moral basis for your decision.

3. Should you discuss the patient's request with the patient's primary care doctor? What is the basis for your decision?
4. What is the position of the Australian Nursing Federation (ANF) on assisted suicide, and how does the ANF position relate to your understanding of your moral obligation?
5. What is your responsibility to the patient and his wife?
6. What ethical and legal issues are involved in taking action or not taking action in this situation?

Reference

Australian and New Zealand Society of Palliative Medicine. (2013). *Position statement on the practice of euthanasia and assisted suicide*. Available at <http://palliativecarewa.asn.au/site/wp-content/uploads/2014/03/ANZSPM-Position-Statement-on-Euthanasia-and-Assisted-Suicide.pdf>.

Australian Nurses Federation. (2012). *Position statement on voluntary euthanasia and assisted suicide*. Available at http://anf.org.au/documents/policies/PS_Voluntary_euthanasia.pdf.

Resources

See Chapter 3 for ethics resources.

palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and physical, psychosocial and spiritual concerns. A similar definition is used by Palliative Care Australia and Hospice New Zealand. In New Zealand, palliative (hospice) care is defined as the care of people who are dying from active, progressive diseases or other conditions that are not responsive to curative treatment. Palliative care embraces the physical, social, emotional and spiritual elements of well-being—*tinana, whānau, hinengaro* and *wairua*—and enhances a person's quality of life while they are dying. Palliative care also supports the bereaved family/*whānau*. Increasingly, palliative care is being offered to patients with non-cancer chronic illnesses, where comprehensive symptom management and psychosocial and spiritual support can enhance the patient's and family's quality of life.

The term *hospice* refers to a place where specially trained doctors, nurses, allied healthcare professionals and others, including volunteers, provide palliative care for people who are dying. Sometimes people go into hospices for a short time to give their carers some respite or to have difficult symptoms addressed. In New Zealand, 'hospice' also refers to the practice of palliative care.

Palliative care, which is conceptually broader than hospice care, is both an approach to care and a structured system for care delivery. Palliative care emphasises management of psychological, social and spiritual problems in addition to control of pain and other physical symptoms. As the definition suggests, palliative care is not care that begins when cure-focused treatment ends. The goal of palliative care is to improve the patient's and family's quality of life, and many aspects of this type of comprehensive, comfort-focused approach to care are applicable earlier in the process of life-limiting disease in conjunction with cure-focused treatment. However, definitions of palliative care, the services that are part of it, and the clinicians who provide it are evolving steadily.

Some would argue that palliative care is no different from comprehensive nursing, medical, social and spiritual care and that patients should not have to be labelled as 'dying' to receive person-focused care and symptom management. In addition to a focus on the multiple dimensions of the illness experience for both patients and their families, palliative care emphasises the interdisciplinary collaboration that is necessary to bring about the desired outcomes for patients and their families. **Interdisciplinary collaboration** is distinguished from multidisciplinary practice in that the former is based on communication and cooperation among the various disciplines; each member of the team contributes to a single care plan that addresses the needs of the patient and family.

Palliative care at the end of life

As discussed previously, palliative care is broadly conceptualised as comprehensive, person- and family-centred care when disease is not responsive to treatment. The broadening

of the concept of palliative care is highlighted by the WHO (2016), whose definition applies to any persons with any diseases (not restricted to cancer) that have a life-limiting phase, are progressive in nature and would benefit from a positive and open attitude towards death and dying. The promotion of a more open approach to discussions of death and dying facilitates identification of people's and families' wishes regarding end-of-life care.

The palliative care approach helps carers, patients and families understand the reality of impending death and how they can all achieve physical, psychological and spiritual well-being. This approach means that palliative care is not limited to the final days and weeks of dying and can contribute to care decisions early in the course of any life-limiting illness, such as advanced renal, respiratory, cardiac or neurological conditions and HIV/AIDS. It can improve the well-being of people in aged-residential care, who, when dying, may be inappropriately transferred to an acute care hospital and consequently die away from the place they regard as 'home'. *Guidelines for a palliative approach in residential aged care* are evidence-based guidelines developed by the Australian Palliative Residential Aged Care (APRAC) project team. The guidelines aim to provide support and guidance for the delivery of a palliative approach in residential aged care (RAC) facilities across Australia (National Health and Medical Research Council, 2015). Subsequently, acknowledgement of the specific needs of people being cared for in their own homes and other community settings resulted in the development of *Guidelines for a palliative approach for aged care in the community setting*, and supporting resources have also been developed (ADHA, 2011; AIHW, 2014).

In Australia and New Zealand, this approach to palliative care is usually provided by palliative care teams, comprising the patient, carers and primary health professionals (GP, community nurse and allied health professionals). The number of palliative patients seen by GPs is usually small. For patients with complex needs, the involvement of an interdisciplinary specialised palliative care service, working alongside primary clinical carers, is considered to be the best approach (PCA, 2005b).

Palliative care nurses are specialist clinicians or nurse practitioners who assess individual, family and home care needs and take the appropriate actions to ensure that such needs are met. They support and encourage their generalist colleagues in positive and practical approaches to palliative care (PCNA, 2015). Palliative care services are now being offered to a wider range of communities in Australia and New Zealand, including older people living in their homes or in RAC settings, Indigenous Australians and Māori and ethnic communities as Australia and New Zealand are becoming increasingly diverse multicultural countries. Nurses and other healthcare professionals need to be knowledgeable and skilled at providing culturally safe and competent care to the terminally ill. Palliative Care Australia has developed multicultural guidelines to assist in the care of the terminally ill. Various resource and training materials are available to assist staff to provide culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples (Australian Department of Health, 2007; Palliative Care Curriculum for Undergraduates [PCC4U], 2014).

Palliative care in the hospital setting

The reasons why patients find themselves in hospitals at the end of life may be a result of patient preference, of sudden deterioration while in hospital or the inability to manage at home when there is no access to a palliative care unit. To deal with this eventuality, many acute-care hospitals now have a palliative care consultancy service. This service is usually provided by an interdisciplinary palliative care team, skilled in symptom control, decision making, care of the dying, management of treatment complications, communication, psychosocial care and coordination of care. Integration of these skills into hospital practice has been shown to enhance the care of terminally ill hospitalised patients (Jackson et al., 2012; O'Connor & Peters, 2009). A pivotal role in the success of consultancy services is provided by the palliative care clinical nurse consultant, who is often the health professional most engaged in facilitating continuity of care across all sectors of the health system. The role was developed in recognition both of the fact that many patients still die in hospitals, as discussed earlier, and that palliative care should be initiated in these acute settings (Jackson et al., 2012; O'Connor & Peters, 2009).

Palliative care in residential care facilities

Over recent years, there has been substantial support funded through a range of aged and disability packages, allowing people who are frail and aged to be cared for in their own homes (Aged Care Financing Authority, 2015; Australian Department of Social Services, 2015); however, a significant number of Australians and New Zealanders still require the services of RAC facilities (AIHW, 2015). Residents in RAC facilities often have complex issues, multiple comorbidities and are highly dependent (Brisbane South Palliative Care Collaborative, 2013). The number of residents who die within residential care has been increasing over the past 20 years and the need for palliative care is recognised as a priority (AIHW, 2015; Brisbane South Palliative Care Collaborative, 2013). Strategies to increase the provision of palliative care to older people in residential care, who have developed a non-malignant illness, a life-limiting illness or their illness has become life-limiting, have been initiated by both Australian and New Zealand governments. The *Guidelines for a palliative approach in residential aged care* (APRAC project, 2006) were developed to provide support and guidance for the delivery of palliative care in RAC across Australia. The continuing challenges for palliative care in residential care include making its provision mainstream for non-malignant conditions as well as for cancers and helping carers recognise that age and site of care are irrelevant. The guidelines emphasise the difference between a palliative approach, specialist palliative care and end-of-life care. End-of-life care is only the stage of palliative care. End-of-life care refers to the last weeks or days of life and during the last days, a resident may have an end-of-life pathway in use. There are many challenges in providing palliative care in residential and community settings. Increased competence in palliative care practice may help to prevent residents who, at the end of life, are most at risk of being inappropriately transferred to

hospital (National Aged Care Alliance, 2012). Despite the fact that most people indicate that they would like to die at home, in the past 50 years, deaths at home have decreased to around 16%; 20% of people die in hospices, 10% in nursing homes; and the rest die in hospital (Karmel et al., 2008). For those who die in aged and supported care facilities, it is unknown how many of these residents received palliative care in the end stages of their life and which proportion of residents might have benefited from access to this type of support.

The hospice care movement

Palliative or hospice care emerged in the 1970s from the voluntary services of the hospice movement. In the first half of the 20th century, community-based charitable organisations established the first hospices to care for people with a life-limiting illness in Australia and New Zealand. The root of the word hospice is *hospes*, meaning 'host'. Historically, hospice referred to a shelter or way station for weary travellers on a pilgrimage. The work of Dame Cicely Saunders, a pioneer of the modern hospice movement in the United Kingdom, led to a recognition of the importance of pain as both a physical and spiritual problem. She opened the St Christopher's Hospice in London in 1967, where she used the concept of 'total pain' in the treatment of her patients (Bennahum, 2003). According to Cicely Saunders, the principles underlying hospice are as follows:

- Death must be accepted.
- The patient's total care is best managed by an interdisciplinary team whose members communicate regularly with one another.
- Pain and other symptoms of life-limiting illness must be managed.
- The patient and the family should be viewed as a single unit of care.
- Home care of the dying is necessary.
- Bereavement care must be provided to family members.
- Research and education should be ongoing.

Her success spread throughout the world and this model has since been adopted by the WHO and 30 countries, including the United Kingdom, Australia and New Zealand. Since its emergence, palliative or hospice care has evolved and developed significantly in Australia, New Zealand and other parts of the world. It is now widely acknowledged in Australia and New Zealand, as in other parts of the world, that there is a need for timely involvement of palliative care services in the management of many people with cancer, acquired immunodeficiency syndrome (AIDS), end-stage organ failure and neurodegenerative diseases.

Palliative care in Australia

It was not until the late 1980s that the responsibility for providing palliative care for people who have a life-limiting illness moved from the services traditionally provided by charitable organisations and volunteers to those provided and funded by government. The first government funding for the delivery of palliative care services, the Australian government's 'Medicare

Incentives Package⁹, was provided to the states and territories in 1988. The Australian government's aim in developing this package was to enable dying patients to die at home in a familiar environment and, wherever possible, to help minimise the need for their hospitalisation. This funding resulted in a rapid rise in the use of palliative services and a decrease in the number of patients with cancer dying in acute care hospitals. The National Palliative Care Strategy is a continuing partnership between the Australian State and Territory Health Departments, palliative care service providers and community-based organisations throughout the country and was funded through the National Palliative Care Program. Under the Council of Australian Governments, significant initiatives such as the National Partnership Agreement on Hospital and Health Workforce Reform have been enacted (ADHA, 2009). Palliative Care Australia (2005b) carried the themes, begun in the National Palliative Care Strategy, further to develop a tiered framework to articulate differing levels of care available for patients requiring palliative management. The framework acknowledges that most people with life-limiting illnesses can be effectively managed by generalist healthcare providers.

The National Palliative Care Program covers the following six broad priority areas:

- Provision of an expanded range of medications for palliative care in the community
- Assistance for families and increased support to other care networks
- Education, training and support for the primary care workforce
- Increasing the range and reach of palliative care services
- Capacity building in the palliative care research community and
- Performance information development (ADHA, 2009).

These government initiatives have led to the provision of designated palliative care programs that deliver a range of services in various settings including hospitals, hospices, homes and RAC facilities. The types of services include admitted patient services, outpatient care, home-based care (provided in the setting in which the patient is living), respite care and bereavement care for the family/carer following the death of the patient. Chart 12-2 summarises the 13 national standards

CHART 12-2 Standards for providing quality palliative care for all Australians

Standard 1

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

Standard 2

The holistic needs of the patients, their carer/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 patients, their carer/s and family.

Standard 4

Care is coordinated to minimise the burden on the patients, their carer/s and family.

Standard 5

The primary carer/s is provided with information, support and guidance about his or her role according to his or her needs and wishes.

Standard 6

The unique needs of dying patients are considered, their comfort maximised 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 patients, their carer/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 life-limiting illness, their carer/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 self-care strategies.

Used with permission from Palliative Care Australia (2005a). *Standards for providing quality palliative care for all Australians* (4th ed.; pp. 6–9). Canberra: Palliative Care Australia (The review of the 5th edition of the Standards began in 2014, including an extensive consultation with the palliative care, aged care and health sectors).

for the provision of quality palliative care for all Australians (PCA, 2005a).

Palliative (hospice) care in New Zealand

As mentioned previously, palliative care services emerged in New Zealand during the early 1970s. Palliative care services are similar to those in Australia and both countries experience common issues and problems. The New Zealand Palliative Care Strategy was introduced in 2001 in response to the increasing number of problems and issues identified by palliative care providers, particularly hospices. The strategy established a systematic and informed approach to the provision and funding of palliative care services to ensure that all people who are dying and their family/*whānau* have access to timely palliative care services that are culturally sensitive and provided in a coordinated manner. Key organisations in New Zealand include Hospice New Zealand, Palliative Care Nurses New Zealand, National Advance Care Planning Cooperative and Regional Cancer Networks. A review of adult palliative care services begun in 2015 (NZMOH, 2015b). The review was led by a project team within the Ministry and supported by a new external advisory group (replacing the Palliative Care Council). The review examines how to continue to provide equitable and high-quality palliative care and to look at the future needs for palliative care services over the next 10 to 20 years. A further government initiative was the publication of *Te Ara Whakapiri: Principles and Guidance for the Last Days of Life* (NZMOH, 2015c) which provides guidance about end-of-life care specific to the unique needs of Aotearoa New Zealand.

Nursing care at the end of life

Many patients suffer unnecessarily when they do not receive adequate attention for the symptoms accompanying serious illness. Careful evaluation of the patient should include not only the physical problems but also the psychosocial and spiritual dimensions of the patient's and family's experience. This approach contributes to a comprehensive understanding of how the patient's and family's life has been affected by the illness and will lead to nursing care that addresses the multidimensional needs.

Psychosocial and regulatory issues

Nurses are responsible for educating patients about the possibilities and probabilities inherent in their illness and their life with the illness and for supporting them as they conduct life review, values clarification, treatment decision making and end-of-life closure. The only effective way to do this is to try to appreciate and understand the illness from the patient's perspective. At the same time, nurses need to be both culturally aware and sensitive in their approaches to communication with patients and families about death. Attitudes towards open disclosure about life-limiting illness vary widely among different cultures (Brown, 2014; Sarafis et al., 2014), and direct

communication with patients about such matters may be viewed as harmful (Barclay et al., 2007). Culture shapes attitudes and how people make meaning out of both living and dying (Mazanec & Panke, 2015). To provide effective patient- and family-centred care at the end of life, nurses must be willing to set aside their assumptions so that they can discover what type and amount of disclosure is most meaningful to each patient and family within their unique belief systems (see Table 12-1).

Advance care planning (ACP) is a term to describe the various ways people can reflect upon and inform health professionals/significant others about what they would like for their future healthcare. Advance care planning involves communicating desires for future care if a person reaches a stage when they are no longer able to make decisions for himself or herself. The social and legal evolution of advance directive documents represents some progress in our willingness to both contemplate and communicate our wishes surrounding the end of life (see Chart 12-3). The legislation and guidelines are evolving, so they need to be regularly reviewed.

CHART 12-3 Methods of stating end-of-life preferences

- **Advance directives:** Written documents that allow the individual of sound mind to document preferences regarding end-of-life care that should be followed when the signer is terminally ill and unable to verbally communicate his or her wishes. The documents are generally completed in advance of serious illness but may be completed after a diagnosis of serious illness if the signer is still of sound mind. The most common types are the durable power of attorney for healthcare and the living will.
- **Durable power of attorney for healthcare:** A legal document through which the signer appoints and authorises another individual to make medical decisions on his or her behalf when they are no longer able to speak for himself or herself. This is also known as a healthcare power of attorney or a proxy directive.
- **Living will:** A type of advance directive in which the individual documents treatment preferences. It provides instructions for care in the event that the signer is terminally ill and not able to communicate his or her wishes directly and often is accompanied by a durable power of attorney for healthcare. This is also known as a medical directive or treatment directive.
- **Physician Orders for Life-Sustaining Treatment (POLST):** A form that translates patient preferences expressed in advance directives to medical 'orders' that are transferable across settings and readily available to all healthcare providers, including emergency medical personnel. The POLST form is a brightly coloured form that specifies preferences related to cardiopulmonary resuscitation and use of IV medications or fluids, antibiotics, artificial nutrition and other medical interventions. The form is signed by the patient or surrogate and the doctor, advanced practice nurse or doctor assistant. The use of the POLST is subject to state laws and regulations. Numerous states have endorsed the POLST or a similar form.

Information about the ACP and state-specific advance directive documents and instructions is available at www.caringinfo.org. Information about the POLST is available at www.ohsu.edu/polst/.

TABLE 12-1 Overview of religious and cultural beliefs and views on death and dying

Religion	General religious/cultural beliefs	Views about death/preparing for death
Buddhism	<ul style="list-style-type: none"> • There is no central authority in the Buddhist religion. • Taboo and religious purity play little, if any, role, and religious law imposes no special requirements for medical treatment. • Treatment by someone of the same gender is preferable. • Cremation is the most common way of disposing of the dead. • Some Buddhists may be unwilling to take pain-relieving medications or strong sedatives. It is believed that an unclouded mind can lead to a better rebirth. • Buddhists believe that after death there is either rebirth or Nirvana—the latter being enlightenment that frees the soul from the cycle of death and rebirth. 	<ul style="list-style-type: none"> • Teachings emphasise the inevitability of death; therefore, Buddhists tend to be psychologically prepared to accept impending death with calmness and dignity. • Death occurs when a body is bereft of vitality, heat and sentiency. Brain death is disputed as meeting the requirements for death. • It is often appropriate to decide that the patient is beyond medical help and to allow events to take their course. In these cases, it is justifiable to refuse or withdraw treatment in light of the overall prognosis. • Buddhism supports the use of hospice.
Hinduism	<ul style="list-style-type: none"> • Each caste has a different view of death. • This life is a transition between the previous life and the next. • Bodies are cremated. During the first 10 days after death, relatives must create a new ethereal body. • Good karma leads to good rebirth or release, and bad karma leads to bad rebirth. 	<ul style="list-style-type: none"> • Many elderly people withdraw into their homes, where they prepare for death through prayer and meditation. • A 'good death' is timely, in the right place (on the ground at home), conscious and prepared, with the mind on God. All affairs should be in order. • A 'bad death' is untimely, violent and unprepared. The worst death is suicide.
Indigenous Australians	<ul style="list-style-type: none"> • Rather than praying to a single god they cannot see, each group of Indigenous Australians generally believes in a number of different deities, whose image is depicted in a tangible, recognisable form. • On the death of a loved one, people conduct rituals, songs and dances to ensure that the person's spirit leaves the area and returns to its birth place, from where it can later be reborn. 	<ul style="list-style-type: none"> • When a death is expected, there is usually a gathering of many family and friends. It is taboo for Indigenous Australians to mention the name of the deceased person. Ask the family for the appropriate word to use instead of their name following death.
Islam	<ul style="list-style-type: none"> • Muslims believe in one God. • God revealed the message of God to Muhammad, the prophet, in the Qur'an (Koran). The Qur'an states that Muslims should maintain a balanced diet and exercise. • Muslim patients may wish to engage in ritual prayer, practised five times during the day. • Fasting during the month of Ramadan is a pillar of Islam. • Completion of the pilgrimage (hajj) to Mecca (money and health permitting), at least once, is also a pillar of Islam. 	<ul style="list-style-type: none"> • Everyone will face death, and the way a person dies is of great individual importance. • Death cannot happen except by God's permission. However, it is recognised that diseases and trauma cause death. • There is a belief that healthcare providers must do everything possible to prevent a premature death. • Pain is a cleansing instrument of God. Pain can also be viewed as having an educational purpose (pain can compensate for sin). • The killing of a terminally ill person is an act of disobedience against God. However, pain relief or withholding or withdrawing of life support when there is no doubt that the person's disease is causing untreatable suffering is permissible as long as there is formal agreement among all parties concerned.
Judaism	<ul style="list-style-type: none"> • Human beings are mortal and their bodies belong to God. • Although the doctor has the authority to determine the appropriate course of treatment, ultimately the patient has the right to choose, as long as the medical regimen follows Jewish law. • Disclosure is important. Most patients want to know the truth. • Jews are obligated to visit the sick. 	<ul style="list-style-type: none"> • Traditional criteria for death are cessation of breathing and heartbeat. Conservative rabbis have accepted brain death as fulfilling these criteria. • Advance directives for healthcare are permissible. • Views on the use of artificial nutrition and hydration vary, depending on the particular sect/movement. • Most rabbis maintain that Jews may enrol in hospice.

(continued)

Religion	General religious/cultural beliefs	Views about death/preparing for death
Māori	<ul style="list-style-type: none"> • Māori believe that all living things descended from the Gods and have a type of soul: the wairua. • A person, an object or a place that is tapu (sacred), may not be touched by human contact. • When a loved one dies, Māori will not leave the body alone. • On death, Māori believe that the spirit travels to the Pohutukawa tree that sits on the very tip of Cape Reinga at the top of the North Island. 	<ul style="list-style-type: none"> • Death is an occasion for family. When the person dies, the Māori believe that the body is not vacated immediately by the spirit. The deceased will be visited at all times and the visitors will be talking and recalling the deceased's life. • The family may wish to handle the deceased's body.
Pacific people	<ul style="list-style-type: none"> • The religious beliefs of Pacific Islanders reflect centuries-long efforts of missionaries to Christianise the area. • In traditional Polynesian belief systems, all things are believed to be endowed with sacred supernatural power. • Such power, known as mana, can be nullified by various human actions and many tapu (taboos) were intended to prevent such behaviour. 	<ul style="list-style-type: none"> • Funeral rites are very important complex and vary depending on the Pacific culture. • It is not uncommon for the families to want to remain with the deceased and they may wish to wash and dress the body.
Traditional Christianity	<ul style="list-style-type: none"> • Christians believe in one God. • The belief in eternal salvation sets Christianity apart. • Beliefs vary. Some Christians hope to attain eternal salvation, and some view the religion more as a culture. • Even within a family, religious views can differ. Some family members may not follow the religion at all. 	<ul style="list-style-type: none"> • Intentionally bringing about death by either omission or commission is prohibited. • The appropriateness of analgesia and sedation to avoid terminal suffering and despair is acceptable, if it does not, by clouding consciousness, take away the final opportunity for repentance. • There is no obligation to postpone death; the attempt to save life at all costs is forbidden. However, there could be a duty to use high-technology medicine to gain a last opportunity for repentance. • Impending death offers a final chance to become reconciled with those whom one has harmed and to ask God's forgiveness. • Liturgical (ceremonial) Christians generally regard last rites as integral to the relationship with God. Repentance can include confessing formally and receiving Communion and final anointing. This often involves particular ministers. • Christians who follow the religion at a cultural level are likely to have secular approaches to end-of-life decisions. • Advance directives allow patients to appoint decision makers and to provide instructions that ensure that their wishes are followed.

Information compiled from Firth, S. (2005). End of life: A Hindu view. *Lancet*, 366(9486), 682–686; Dorff, E. N. (2005). End of life: Jewish perspectives. *Lancet*, 366(9488), 862–865; Keown, D. (2005). End of life: The Buddhist view. *Lancet*, 366(9489), 952–955; Sachedina, A. (2005). End of life: The Islamic view. *Lancet*, 366(9487), 774–779; Salman, K., & Zoucha, R. (2010). Considering faith within culture when caring for the terminally ill Muslim patient. *Journal of Hospice and Palliative Nursing*, 12(3), 156–163; Engelhardt, H. T., & Smith Iltis, A. (2005). End of life: The traditional Christian view. *Lancet*, 366(9490), 1045–1049; Australian Government Department of Health and Ageing (DoHA). (2004). Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples: Resource kit. Viewed March 2015 at <http://webarchive.nla.gov.au>; bpacNZ. (2006). Providing palliative care to Māori. Available March 2015 at www.bpac.org.nz/resources/campaign/palliative/palliative_maori.asp; Medical Council of New Zealand. (2010). Best health outcomes for Pacific peoples: Practice implications. Available at www.mcnz.org.nz; www.aboriginalculture.com.au/religion.shtml; <http://history-nz.org/maori6.html>; www.britannica.com/place/Polynesia.

New Zealand's Advanced Medical Directive (written or oral) is legislated under the Health and Disability Consumers' Rights Code (NZMOH, 2011). Advance directives are written documents that allow an individual of sound mind to document his or her preferences regarding the use or non-use of medical treatment at the end of life, specify the preferred setting for care, and communicate other valuable insights

into his or her values and beliefs (Australian Department of Health, 2015). The addition of a proxy directive (the appointment and authorisation of another individual to make medical decisions on behalf of the author of the advance directive when they can no longer speak for himself or herself) is an important addition to the 'living will' or medical directive that specifies the signer's preferences. Although

these documents are widely available from healthcare providers, government organisations, bookstores and online, their underuse reflects society's continued discomfort with openly confronting the subject of death. Furthermore, the existence of a properly executed advance directive does not reduce the complexity of end-of-life decisions, nor does it substitute effective communication between healthcare provider, patient and family as end-of-life approaches (Lovell & Yates, 2014; Rhee et al., 2012; Stevenson & O'Donnell, 2015).

Communication

In the past, palliation was often all that could be offered to patients with cancer, but medical and technological developments have seen a dramatic shift in survival rates and a reduction in palliative care education for health professionals (Wittenberg-Lyles et al., 2014). Consequently, health professionals may feel less prepared or comfortable with truth telling, particularly when conveying bad news.

To develop a level of comfort and expertise in communicating with seriously and terminally ill patients and their families, nurses and other clinicians need to first consider their own experiences with and values concerning illness and death. Reflection, reading and talking with family members, friends and colleagues can assist the nurse to examine beliefs about death and dying. Talking with individuals from differing cultural backgrounds can help the nurse to view personally held beliefs from a different perspective and can help to sensitise the nurse to death-related beliefs and practices in other cultures. Values, clarification and personal death awareness exercises can provide a starting point for self-discovery and discussion.

Skills for communicating with the seriously ill

Nurses need to develop skill and comfort in assessing patients' and families' responses to serious illness and planning interventions that will support their values and choices throughout the continuum of care (Back et al., 2009). Patients and families need ongoing assistance: telling a patient something once is not teaching, and hearing the patient's words is not the same as active listening. Throughout the course of a serious illness, patients and their families will encounter complicated treatment decisions, bad news about disease progression and recurring emotional responses. In addition to the time of initial diagnosis, lack of response to the treatment course, decisions to continue or withdraw particular interventions and decisions about palliative care are examples of critical points on the treatment continuum that demand patience, empathy and honesty from the nurse.

Although communication with each patient and family should be tailored to their level of understanding and values concerning disclosure, general guidelines for the nurse include the following (Balzer Riley, 2011):

- Deliver and interpret the technical information necessary for making decisions without hiding behind medical terminology.

- Create a peaceful environment and plan ahead, if you can, to reduce the risk of interruptions.
- Be fully present and relate to the person, not the illness.
- Be attentive, without judgement, to what the patient has to say instead of offering automatic reassurances.
- Allow the patient and the family to set the agenda regarding the depth of conversation.

Nursing interventions when the patient and the family receive bad news

Communicating about a life-limiting diagnosis or about disease progression is best accomplished by the interdisciplinary team in settings where these are available—a doctor, nurse and social worker should be present whenever possible to provide information, facilitate discussion and address concerns. Most importantly, the presence of the team conveys caring and respect for the patient and the family. Creating the right setting is particularly important. If the patient wishes to have family present for the discussion, arrangements should be made to have the discussion at a time that is best for the patient and the family. A quiet area with minimal disturbances should be used. Each clinician who is present should turn off pagers or other communication devices for the duration of the meeting and should allow sufficient time for the patient and the family to absorb and respond to the news. Finally, the space in which the meeting takes place should be conducive to seating all of the participants at eye level. It is difficult enough for patients and families to be the recipients of bad news without having an array of clinicians standing uncomfortably over them at the foot of the patient's bed (see Chart 12-4).

After an initial discussion of a life-limiting illness or progression of a disease, patients and their families will have many questions and may need to be reminded of factual information. Coping with news about a serious diagnosis or poor prognosis is an ongoing process. The nurse needs to be sensitive to these ongoing needs and may need to repeat previously provided information or simply be present while the patient and the family react emotionally. The most important intervention the nurse can provide is listening empathetically. Seriously ill patients and their families need time and support to cope with the changes brought about by serious illness and the prospect of impending death. The nurse who is able to listen without judging and without trying to solve the patient's and family's problems provides an invaluable intervention. Keys to effective listening include the following:

- Resist the impulse to fill the 'empty space' in communication with talk.
- Allow the patient and the family sufficient time to reflect and respond after asking a question.
- Prompt gently: 'Do you need more time to think about this?'
- Avoid distractions (noise, interruptions).
- Avoid the impulse to give advice.
- Avoid 'canned' or generic responses: 'I know just how you feel.'

CHART 12-4
COMFORT: A framework for communication in palliative care**Communication (C)**

- Narrative clinical practice: Elicit and be fully present for the patient's and family's story.
- Verbal clarity: Use compassionate, non-ambiguous language.
- Non-verbal immediacy: Use eye contact, body position and self-awareness to show attentiveness.

Orientation (O)

- Support health literacy.
- Acknowledge vulnerability.
- Express cultural sensitivity.

Mindfulness (M)

- Stay in the moment: Avoid scripted responses.
- Avoid prejudgement: Do not have expectations that this patient and family will or should respond as others have in the past.
- Adapt to rapid changes: Be ready to shift to new topics and concerns that are revealed.

Family (F)

- Think of the family as a 'second-order' patient: The family and the patient comprise the unit of care.
- Know that the family is a bridge to the patient: You must gain the family's trust to work effectively.

- Use family meetings (patient included) to clarify goals for treatment.

Openings (O)

- Address essential transitions in care or status.
- Seek a higher level of understanding of the disease process.
- Engage spiritual concerns.

Relating (R)

- Prioritise the turning point in illness.
- Understand that communication should be non-linear: The patient and family may need to revisit topics multiple times and on multiple occasions.
- Know that the patient's and family's acceptance must drive communication.

Team (T)

- The interdisciplinary team includes members trained in various aspects of palliative care.
- Assure the patient and the family that they will not be abandoned.
- Assure continuity of care across settings: Goals and plans should be clearly communicated to other providers.

Adapted with permission from Wittenberg-Lyles, E., Goldsmith, J., & Ragan, S. L. (2010). The COMFORT initiative: Palliative nursing and the centrality of communication. *Journal of Hospice and Palliative Nursing*, 12(5), 282–292.

- Ask questions.
- Assess understanding—your own and the patient's—by restating, summarising and reviewing.

Responding with sensitivity to difficult questions

Patients will often direct questions or concerns to nurses before they have been able to fully discuss the details of their diagnosis and prognosis with the doctor or the entire health-care team. Using open-ended questions allows the nurse to elicit concerns, explore misconceptions and needs for information and form the basis for collaboration with the doctor and other team members.

For example, the seriously ill patient may ask the nurse, 'Am I dying?' The nurse should avoid making unhelpful responses that dismiss the patient's real concerns or defer the issue to another care provider. Nursing assessment and intervention are always possible, even when a need for further discussion with the doctor is clearly indicated. Whenever possible, discussions in response to the patient's concerns should occur when the patient expresses a need, although it may be the least convenient time for the nurse. Creating an uninterrupted space of just five minutes can do much to identify the source of the concern, allay anxieties and plan for follow-up.

In response to the question, 'Am I dying?', the nurse could establish eye contact and respond by acknowledging the patient's fears ('This must be very difficult for you') and an open-ended statement or question ('Tell me more about what is on your mind?'). The nurse then needs to listen intently, ask

additional questions for clarification and provide reassurance only when it is realistic. In this example, the nurse might quickly ascertain that the patient's question emanates from a need for specific information—about diagnosis and prognosis from the doctor, about the physiology of the dying process from the nurse or perhaps about financial implications for the family from the social worker. The pastoral care worker may also be called to talk with the patient about existential concerns.

As a member of the interdisciplinary team caring for the patient at the end of life, the nurse fills an important role in facilitating the team's understanding of the patient's values and preferences, the family dynamics concerning decision making and the patient's and family's response to treatment and changing health status. Many dilemmas in patient care at the end of life are related to poor communication between team members and the patient and family and failure of team members to communicate effectively with each other. Regardless of the care setting, the nurse can ensure a proactive approach to the psychosocial care of the patient and the family. Periodic, structured assessments provide an opportunity for all parties to consider their priorities and plan for an uncertain future. The nurse can assist the patient and the family to clarify their values and preferences concerning end-of-life care by using a structured approach. Sufficient time must be devoted to each step so that the patient and the family have time to process new information, formulate questions and consider their options. The nurse may need to plan several meetings to accomplish the steps described in Chart 12-4.

Providing culturally sensitive care at the end of life

Although death, grief and mourning are universally accepted aspects of living, values, expectations and practices during serious illness, as death approaches, and following death are often culturally dependent. Healthcare providers may share very similar values concerning end-of-life care and may find that they are inadequately prepared to assess and implement care plans that support culturally diverse perspectives. Cultural sensitivity in palliative care challenges health professionals to not only respect the beliefs and values of others but also be willing to adjust their practice to accommodate cultural needs (McGee & Johnson, 2014; Palliative Care Expert Group [PCEG], 2010). Historical mistrust of the healthcare system and unequal access to even basic medical care may underlie the beliefs and attitudes among ethnically diverse populations (see Table 12-1). In addition, lack of education or knowledge concerning end-of-life care treatment options and language barriers influence decisions among many socioeconomically disadvantaged groups. Professional health interpreters can be invaluable for groups isolated by language.

Much of the formal structure concerning healthcare decisions in Australia and New Zealand is rooted in the Western notions of autonomy, truth telling and the acceptability of withdrawing or withholding life-prolonging medical treatment at the end of life. Yet, in many cultures, interdependence is valued over autonomy which can come into conflict with Western medicine and expectations (Sarafis et al., 2014). In addition, there is variation in preference regarding the use of life-prolonging medical treatments such as cardiopulmonary resuscitation and artificially provided nutrition and hydration at the end of life; some groups are less likely to agree with withholding or withdrawing such life support in life-limiting illness.

The nurse's role is to assess the values, preferences and practices of every patient, regardless of ethnicity, socioeconomic status or background. The nurse can share knowledge about the patient's and family's cultural beliefs and practices with the healthcare team and facilitate the adaptation of the care plan to accommodate these practices.

The nurse should assess and document the patient's and family's specific beliefs, preferences and practices regarding end-of-life care, preparation for death and after death rituals. Chart 12-5 identifies topics that the nurse should cover and questions that the nurse may use to elicit the information.

CHART 12-5 ASSESSMENT

Assessing end-of-life care beliefs, preferences and practices

Disclosure/truth telling: 'Tell me how you/your family talk about very sensitive or serious matters.'

- Content: 'Are there any topics that you or your family are uncomfortable discussing?'
- Person responsible for disclosure: 'Is there one person in the family who assumes responsibility for obtaining and sharing information?'
- Disclosure practices regarding children: 'What kind of information may be shared with children in your family, and who is responsible for communicating with the children?'
- Sharing of information within the family or community group: 'What kind/how much information should be shared with your immediate family? Your extended family? Others in the community (e.g. members of a religious community)?'

Decision-making style: 'How are decisions made in your family? Who would you like to be involved in decisions about your treatment or care?'

- Individual
- Family-centred
- Family elder or patriarch/matriarch
- Deference to authority (such as the doctor)

Symptom management: 'How would you like us to help you to manage the physical effects of your illness?'

- Acceptability of medications used for symptom relief
- Beliefs regarding expression of pain and other symptoms
- Degree of symptom management desired

Life-sustaining treatment expectations: 'Have you thought about what type of medical treatment you/your significant other

want(s) as the end of life is nearing? Do you have an advanced directive (living will and/or enduring power of attorney)?'

- Nutrition/hydration at the end of life
- Cardiopulmonary resuscitation
- Ventilator
- Dialysis
- Antibiotics
- Medications to treat infection

Desired location of dying: 'Do you have a preference about being at home or in some other location when you die?'

- Desired role for family members in providing care: 'Who do you want to be involved in caring for you at the end of life?'
- Gender-specific prohibitions: 'Are you uncomfortable having either males or females provide your care or your significant other's personal care?'

Spiritual/religious practices and rituals: 'Is there anything that we should know about your spiritual or religious beliefs regarding death? Are there any practices that you would like us to observe as death is nearing?'

Care of the body after the death: 'Is there anything that we should know about how a body/your body should be treated after death?'

Expression of grief: 'What types of losses have you and your family experienced? How do you and your family express grief?'

Funeral and burial practices: 'Are there any rituals or practices associated with funerals or burial that are especially important to you?'

Mourning practices: 'How have you and your family carried on after a loss in the past? Are their particular behaviours or practices that are expected or required?'

The nurse must use judgement and discretion about the timing and setting for eliciting this information. The nurse should give the patient and the family a context for the discussion, such as: It is very important to us to provide care that addresses your needs and the needs of your family. We want to honour and support your wishes, and want you to feel free to tell us how we are doing, and what we could do to better meet your needs. I'd like to ask you some questions; what you tell me will help me to understand and support what is most important to you at this time. You don't need to answer anything that makes you uncomfortable. Is it all right to ask some questions?

The assessment of end-of-life beliefs, preferences and practices will probably need to be carried out in short segments over a period of time (e.g across multiple days of an inpatient hospital stay or in conjunction with multiple patient visits to an outpatient setting).

Palliative Care Australia (1999) released multicultural palliative care guidelines for some 20 language groups to assist nurses and other healthcare workers deliver care in culturally sensitive ways. A comprehensive resource about providing culturally appropriate care to indigenous Australians was developed for the ADHA (2007). In New Zealand, recommendations to improve understanding of ways to increase access and quality of palliative care services for *Māori* patients and their *whānau* have been outlined (NZMOH, 2014). Most healthcare organisations will have their own policies and protocols relating to this important issue. Identification of difference is not intended to encourage stereotyping, but rather to serve as a framework to help healthcare workers better understand and respond to certain behaviours, rituals and practices they may not be familiar with (Loseth et al., 2005).

Goal setting in palliative care at the end of life

As the treatment goals begin to shift in the direction of comfort over cure, symptom relief and patient-/family-defined quality of life assume greater prominence in treatment decision

making. Patient, family and clinicians may all be accustomed to an almost automatic tendency to pursue exhaustive diagnostic testing to locate and treat the source of the patient's illness or symptoms. Each decision to withdraw treatment or discontinue diagnostic testing will be an extremely emotional one for the patient and the family. They may fear that the support from healthcare providers on which they have come to rely will be withdrawn along with the treatment.

As discussed earlier, an ACP may ensure respect of patient choices and autonomy, but despite this, the uptake of people completing an ACP has been limited (Lovell & Yates, 2014; Stevenson & O'Donnell, 2015). Even if an ACP has been completed or a substitute decision maker appointed, there may still be important decisions that had not been previously considered (Stevenson & O'Donnell, 2015).

Throughout the course of the illness, and especially as the patient's functional status and symptoms indicate approaching death, clinicians need to assist the patient and the family to weigh the benefits of continued diagnostic testing and disease-focused medical treatment against the burdens of those activities. The nurse should collaborate with other members of the interdisciplinary team to share assessment findings and develop a coordinated plan of care (see Fig. 12-1). In addition, the nurse may assist the patient and the family to clarify their goals, expected outcomes and values as they consider treatment options (see Chart 12-6).

Spiritual care

Attention to the spiritual component of the patient's and family's illness experience is not new within the context of nursing care, yet many nurses lack the comfort or skills to assess and intervene in this dimension. An Australian study of spiritual care by both acute and palliative care nurses found that although both groups identified time constraints as a major barrier to effective spiritual care, palliative care nurses demonstrated more advanced skills in both delivery of spiritual care and comfort with their personal spiritual dimension (Ronaldson et al., 2012).

CHART 12-6 ASSESSMENT

Assessing the patient and family perspective: Goal setting in palliative care

Awareness of diagnosis, illness stage and prognosis

- 'Tell me your understanding of your illness right now.'

Values

- 'Tell me what is most important to you as you are thinking about the treatment options available to you/your significant other.'

Preferences

- 'You've said that being comfortable and pain-free is most important to you right now. Where would you like to receive

care (home, hospital, residential care facility, doctor's office), and how can I help?'

Expected/desired outcomes

- 'What are your hopes and expectations for this (diagnostic test [e.g. CT scan] or treatment)?'

Benefits and burdens

- 'Is there a point at which you would say that the testing or treatment is outweighed by the burdens it is causing you (e.g. getting from home to the hospital, pain, nausea, fatigue, interference with other important activities)?'

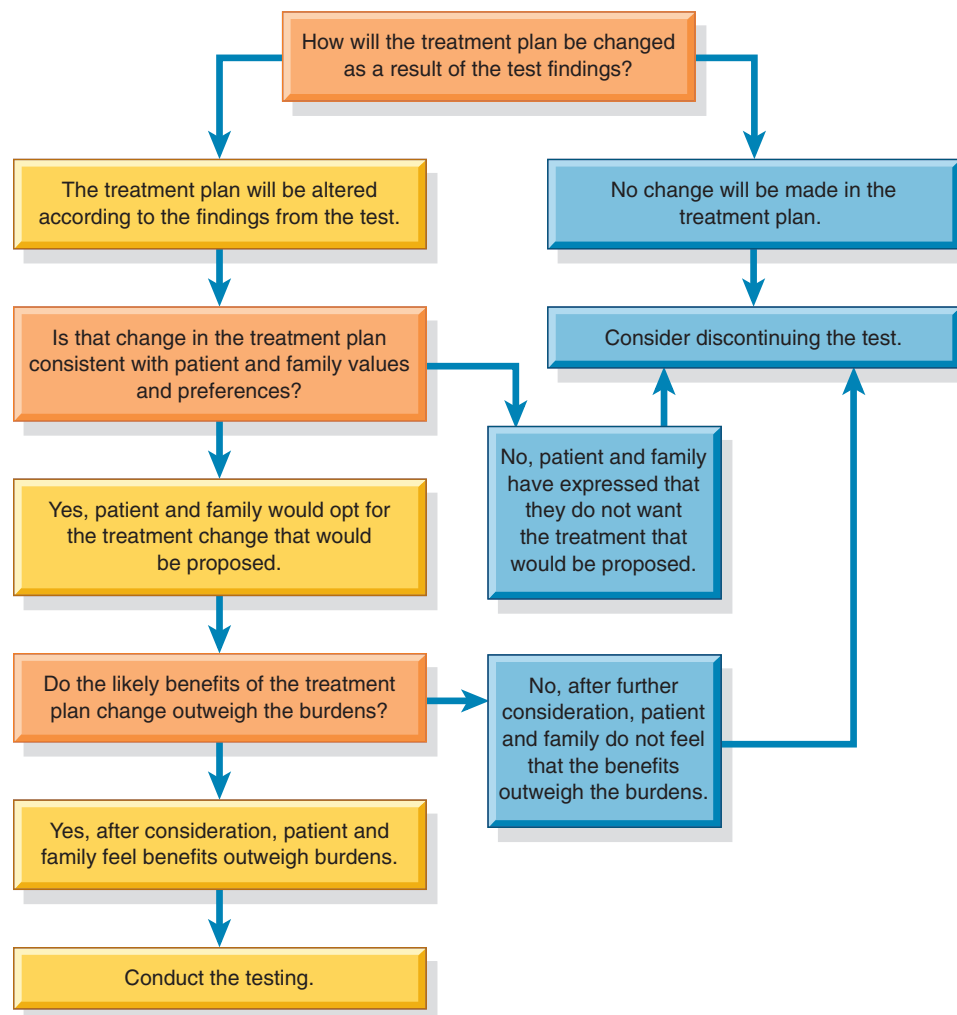


FIGURE 12-1 An algorithm for decision making about diagnostic testing at the end of life.

Spirituality contains features of religiosity, but the two concepts are not interchangeable (Taylor, 2015). Spirituality involves ‘one’s relationship with the transcendent questions that confront one as a human being and how one relates to those questions’ (Taylor, 2015). Spiritual assessment is a key component of comprehensive nursing assessment for patients at the end of life and their families. Although the nursing assessment may include religious affiliation, spiritual assessment is conceptually much broader than religion and, therefore, is relevant regardless of a patient’s expression of religious preference or affiliation. In addition to assessment of the role of religious faith and practices, important religious rituals and connection to a religious community (see Table 12-1), the nurse should further explore:

- The harmony or discord between the patient’s and the family’s beliefs
- Other sources of meaning, hope and comfort
- The presence or absence of a sense of peace of mind and purpose in life
- Spiritual or religious beliefs about illness, medical treatment and care of the sick.

CLINICAL REASONING CHALLENGE

You are a community palliative care nurse and you have been assigned to care for a 34-year-old father of three in the end stages of motor neuron disease. He was discharged from the hospital yesterday and is being admitted to your local home palliative care program. During the admission assessment, when you ask him about his religion and beliefs as part of the spiritual assessment that is performed at the time of admission, he says to you, ‘I don’t go to church anymore and I really don’t have time for people who want to talk about religion.’ Should you respond to his comment? If not, why not? If so, what will you say? Should you continue with part or all of the spiritual assessment? Explain your rationale. If you continue with the spiritual assessment, what questions would you use in the assessment? Discuss your plan for follow-up.

Hope

In life-limiting illness, hope represents patients’ imagined future, forming the basis of a positive, accepting attitude and providing their lives with meaning, direction and optimism. When hope is viewed this way, it is not limited to cure of the disease and instead focuses on what is achievable in the time

remaining (Pattison & Lee, 2011). Many patients find hope in working on important relationships and creating legacies. The patient at the end of life can be extremely resilient, reconceptualising hope repeatedly.

The concept of hope has been delineated and studied by numerous nurse researchers, and its presence has been related to concepts such as spirituality, quality of life and transcendence. Hope is a multidimensional construct that provides comfort as a person endures life threats and personal challenges. Buckley and Herth (2004) identified the following categories of hope-fostering and hope-hindering activities among terminally ill hospice patients with various diagnoses:

- *Hope-fostering categories:* Love of family and friends, spirituality/faith, setting goals and maintaining independence, positive relationships with clinicians, humour, personal characteristics and uplifting memories
- *Hope-hindering categories:* Abandonment and isolation, uncontrollable pain/discomfort and devaluation of personhood

The nurse can support the patient and the family by using effective listening and communication skills and encouraging realistic hope that is specific to the patient's and family's needs for information, expectations for the future and values and preferences concerning the end of life. It is important for the nurse to engage in self-reflection and identify her or his own biases and fears concerning illness, life and death. As nurses become more skilled in working with seriously ill patients, they can become more willing to listen and more comfortable with silence, grief, anger and sadness, and better able to engage with the dying person's story.

Nursing interventions for enabling and supporting hope include:

- Listening attentively
- Encouraging sharing of feelings
- Providing accurate information
- Encouraging and supporting patient's control over his or her circumstances, choices and environment whenever possible
- Assisting the patient to explore ways for finding meaning in his or her life
- Encouraging realistic goals
- Facilitating effective communication within the family
- Making referrals for psychosocial and spiritual counselling
- Assisting with the development of supports in the home or community when none exist.

Managing physiological responses to illness

Patients approaching the end of life experience many of the same symptoms, regardless of their underlying disease processes. There is a worldwide commitment to providing palliation to all who require it, irrespective of the underlying cause of the illness, malignant or non-malignant (Downing, 2015). Symptoms in life-limiting illness may be caused by the disease either directly or, by the treatment of the disease, or by a

CHART 12-7 ASSESSMENT

Assessing symptoms associated with end of life

The efficacy of an assessment of symptoms rests on not only the accuracy of the assessment data collected but the manner in which it is collected. Rostron and Zollo (2012) have developed a mnemonic to guide holistic symptom assessment.

Attitude

Setting the scene

Sitting down/body language

Encouraging discussion

Symptom assessment tools

Symptoms can change frequently and rapidly

Multidisciplinary

Enough is enough

Never assume

Time management.

The mnemonic supports a caring attitude, encouraging discussion, using credible assessment tools, frequent assessment and response to symptoms, involving the multidisciplinary team, suspending assessment when the person is fatigued and never assuming what the main issue might be.

Adapted from Rostron, D., & Zollo, J. (2012). Symptom assessment in palliative care. In O'Connor, M., Lee, S., & Aranda, S. (Eds.), *Palliative Care Nursing: A guide to practice* (3rd ed., pp. 77–91). Melbourne: Ausmed Publication.

coexisting disorder that is unrelated to the disease. Chapter 9 presents assessment principles for pain that include identifying the effect of the pain on the patient's life, the importance of believing the patient's report of the pain and its effect and the importance of systematic assessment of pain. Similarly, symptoms such as dyspnoea, nausea, weakness and anxiety should be as carefully and systematically assessed and managed. Questions that guide the assessment of symptoms are listed in Chart 12-7.

The goals of symptom management at the end of life are to completely relieve the symptom when possible or to decrease it to a level that the patient can tolerate. Of primary importance is the dynamic nature of a patient's situation which, therefore, requires comprehensive initial and ongoing symptom assessment, tracking and evaluation of treatments or interventions and the application of practice based on the best evidence available, or evidence-based practice (EBP). Medical interventions may be aimed at treating the underlying causes of the symptoms. Pharmacological and non-pharmacological methods for symptom management may be used in combination with medical interventions to modify the physiological causes of symptoms.

The patient's goals take precedence over the clinicians' goals to relieve all symptoms at all costs. Although clinicians may believe that symptoms must be completely relieved whenever possible, the patient might choose instead to decrease symptoms to a tolerable level rather than to relieve them completely if the side effects of medications are unacceptable. This often allows the patient to have greater independence, mobility and alertness and to devote attention to issues they consider of higher priority and greater importance.

Anticipating and planning interventions for symptoms that have not yet occurred is a cornerstone of end-of-life care, which has been significantly improved in primary care and acute settings by the use of integrated care pathways, which are care templates or 'maps'. Pathways for care of the dying have been developed and used, particularly in acute care settings, to provide prompts and guidelines for use by generalist health professionals (Jackson et al., 2009). The Liverpool Care Pathway (LCP) was developed at the Royal Liverpool University hospital and was inspired by identified inadequacies in care for the dying in hospital and other acute settings (UK Department of Health, 2013a). The LCP was recommended as a model of care that would transfer best practice and the principles of palliative care for people dying in hospitals and other settings (Ramasamy Venkatasalu et al., 2015). The pathway consisted of care goals, suggested interventions, algorithms and flow charts against which care could be tracked and evaluated. An independent review of the LCP was conducted following reports from the media and others sources that patients were wrongly being denied nutrition and hydration and dying prematurely due to mistreatment using the LCP (Tingle, 2013; Wrigley, 2015). The LCP was phased out in the United Kingdom, as recommended by the Neuberger Review. A major criticism was that the LCP was poorly implemented by the staff and the document was used as a 'tick box' exercise rather than recognising the needs of individual patients (UK Department of Health, 2013b). A lack of patient and family involvement and poor communication may have also been other factors which led to the inappropriate use of the LCP (Venkatasalu et al., 2015).

The Pathway for Improving the Care of the Dying (PICD) is an Australian adaptation of the Liverpool Care Pathway (Jackson et al., 2009). What the researchers learned from a pilot study was that early career health professionals appreciated the support offered by PICD, extensive education on the care pathway and continuing support for health professionals was necessary to help maintain focus, and that it was most relevant for dying patients who did not have complex care needs (Jackson et al., 2009).

Both patients and family members cope more effectively with new symptoms and exacerbations of existing symptoms when they know what to expect and how to manage it. In Australia and New Zealand, community or palliative care nurses or GPs regularly visit patients and their families to ensure that the patient is receiving adequate pain relief for new or existing symptoms. They also provide education about any knowledge deficits that the carer may have regarding pain, medications, comfort therapies and general comfort measures.

Pain

In the final stages of illnesses such as cancer, AIDS, heart disease, COPD and renal disease, pain and other symptoms are common (Caresearch, 2015a; Romem et al., 2015). Despite abundant literature and WHO guidelines for pain management, pain remains undertreated (Lovell et al., 2013; Weingart et al., 2012) (see Chart 12-8). Prevalence of pain is as high as 60% during treatment and up to 90% in advanced stages in patients

with cancer of any type (Weingart et al., 2012) as well as in terminally ill patients with common non-cancer diagnoses.

Pain is the most feared consequence for those approaching end of life and can be caused by the underlying disease, treatments, increasing debility and comorbidities (PCEG, 2010). Pain control is achievable in most cases, even in the last days of life but requires frequent assessment and reassessment (Weingart et al., 2012). Poorly managed pain affects the psychological, emotional, social and financial well-being of patients. Despite studies demonstrating the negative effects of inadequate pain management, practice has been slow to change (Gordon et al., 2009).

Patients who have an established regimen of analgesics should continue to receive those medications as they approach the end of life. Inability to communicate pain should not be equated with the absence of pain. Concentrated morphine solution can be very effectively delivered by the sublingual route, because the small liquid volume is well tolerated even if swallowing is not possible. While most pain can be managed effectively using the oral route, as the end of life nears, patients may be less able to swallow oral medications because of somnolence or nausea. Patients who have been receiving opioids should continue to receive equianalgesic doses via alternate routes. As long as the patient continues to receive opioids, a regime to combat constipation must be implemented. If the patient cannot swallow laxatives or stool softeners, rectal suppositories or enemas may be necessary.

The nurse should educate the family about continuation of comfort measures as the patient approaches the end of life, how to administer analgesics via alternative routes and how to

CHART 12-8 NURSING RESEARCH PROFILE: EVIDENCE-BASED PRACTICE

Use of observational pain scales in critically ill adults

Sites, M. (2013). Observational pain scales in critically ill adults. *Critical Care Nurse*, 33(3), 68–78.

Summary

Pain is a common and distressing symptom in critically ill patients. A systematic assessment of pain is difficult when patients are non-communicative and unable to self-report pain. This study found that although several tools have been developed to identify objective measures of pain, the best tool has yet to be identified, and rates of uncontrolled pain in critically ill patients remain unacceptably high. A systematic assessment of pain should be done routinely, and self-report by the patient should be the primary basis for pain evaluation whenever possible.

Nursing implications

The routine assessment of pain with an observational pain assessment instrument can decrease intensive care unit length of stay, decrease the duration of mechanical ventilation and increase the satisfaction of patients, patients' family members and healthcare providers. Of the available observational pain scales, the Critical-Care Pain Observation Tool has shown superior reliability and validity when used in non-verbal critically ill adults. However, it should be used cautiously in evaluating patients who have chronic pain or concurrent delirium.

assess for pain when the patient cannot verbally report pain intensity. If the patient is at home, family members administering short-acting analgesics need to be educated about the possibility that the patient approaching the end of life will die in close proximity to the time of analgesic administration. They will need reassurance that they did not 'cause' the death of the patient by administering a dose of analgesic medication.

Dyspnoea

Dyspnoea is an uncomfortable awareness of breathing that is common in patients approaching the end of life (Kamal et al., 2012). It is often not associated with blood gases measurement, respiratory rate or oxygen saturation but may be a cause of anxiety and subjective distress for the patient and the family. Patients with primary lung tumours, lung metastases, pleural effusion and restrictive lung disease are likely to experience significant dyspnoea, but up to 50% of all patients with advanced disease will experience some dyspnoea (Mahler et al., 2010). Although the underlying cause of dyspnoea can be identified and treated in some cases, the burdens of additional diagnostic evaluation and treatment aimed at the physiological problem may outweigh the benefits. The treatment of dyspnoea varies depending on the patient's general physical condition and imminence of death. For example, a blood transfusion may provide temporary symptom relief for the anaemic patient earlier in the disease process; however, as the patient approaches the end of life, the benefits are typically short-lived or absent.

Concept Mastery Alert

Dyspnoea is a subjective finding, as is pain. Therefore, a numeric rating scale similar to one that is used for assessing pain provides objective evidence of the severity of the patient's dyspnoea.

Nursing assessment and intervention

As is true in pain assessment and management, the patient's report of dyspnoea must be believed. Also, like the experience of physical pain, the meaning of the dyspnoea to the patient may increase his or her suffering. For example, the patient may interpret increasing dyspnoea as a sign that death is approaching. For some patients, sensations of breathlessness may invoke frightening images of drowning or suffocation, and the resulting cycle of fear and anxiety may create even greater sensations of breathlessness. Therefore, the nurse should conduct a careful assessment of the psychosocial and spiritual components of the symptom (see Chart 12-9).

To determine the intensity of the symptom and its interference with daily activities, patients can be asked to self-report using a scale of 0 to 10, where 0 is no dyspnoea and 10 is the worst imaginable dyspnoea. Measurement of the patient's baseline observations before treatment, during exacerbation of the symptom, during treatment and whenever the treatment plan changes provides ongoing objective evidence for the efficacy of the treatment. In addition, physical assessment findings may assist in identifying the cause of the dyspnoea and selecting nursing interventions to relieve the symptoms. The components of the assessment will change as the patient's condition changes. For example, when the patient who has been on daily weighing can no longer get out of bed, the goal of comfort may outweigh the benefit of continued weighting. Like other symptoms at the end of life, dyspnoea can be managed effectively in the absence of assessment and diagnostic data (i.e. arterial blood gases) that are standard when the patient's illness or symptom is reversible.

Nursing management of dyspnoea at the end of life is directed towards administering medical treatment for the underlying pathology, monitoring the patient's response to treatment, assisting the patient and the family to manage

CHART 12-9 Palliative nursing interventions for dyspnoea

Decrease anxiety

- Administer prescribed anxiolytic medications as indicated for anxiety or panic associated with dyspnoea.
- Assist with relaxation techniques, guided imagery.
- Provide the patient with a means to call for assistance (call bell/light within reach in a hospital or residential care facility; hand-held bell or other device for home).

Treat underlying pathology

- Administer prescribed bronchodilators and corticosteroids (obstructive pathology).
- Administer blood products, erythropoietin as prescribed (typically not beneficial in advanced disease).
- Administer prescribed diuretics and monitor fluid balance (this would not be necessary in advanced disease).

Alter perception of breathlessness

- Administer prescribed oxygen therapy via nasal cannula, if tolerated; masks may not be well tolerated because of feelings of claustrophobia often experienced by dyspnoeic patients.

- Administer prescribed low-dose opioids via oral or subcutaneous route.
- Provide air movement in the patient's environment with a portable fan.
- Open windows if this is possible.
- Ensure that doors are open to give to feeling of space.

Reduce respiratory demand

- Teach the patient and the family to implement energy conservation measures.
- Suggest that family members roster their visits so that the patient is not overwhelmed by visitors and also given time to rest.
- Place needed equipment, supplies and nourishment within reach.
- Offer bedside commode, electric bed (with head that elevates).
- Encourage the patient to rest immediately before and after any activities.
- Shower the patient in commode chair or bed bath to reduce effort.

anxiety (which exacerbates dyspnoea), altering the perception of the symptom and conserving energy (see Chart 12-10). Pharmacological intervention is aimed at modifying lung physiology and improving performance as well as altering the perception of the symptom. Bronchodilators and corticosteroids are examples of medications used to treat underlying obstructive pathology, thereby improving overall lung function. Low-dose oral opioids can reduce the sensation of breathlessness without respiratory depression (PCEG, 2010). Although dyspnoea in life-limiting illness is typically not associated with diminished blood oxygen saturation, low-flow oxygen often provides psychological comfort to the patient and the family, particularly in the home setting.

As previously mentioned, dyspnoea may be exacerbated by anxiety, and anxiety may trigger episodes of dyspnoea, setting off a respiratory crisis in which patient and family may panic. For patients receiving care at home, patient and family instruction should include anticipation and management of crisis situations and a clearly communicated emergency plan. Anxiolytics can be very effective in managing anxiety and reducing breathlessness (PCEG, 2010). Benzodiazepine tolerance can be an issue for those patients who have had long-term management with these types of drugs. In such cases, high doses of benzodiazepines will be required, or opioids alone will be used for dyspnoea (PCEG, 2010). Patients and families should be instructed on medication administration, condition changes that should be reported to the doctor and the nurse and strategies for coping with diminished reserves and increasing symptomatology as the disease progresses. The patient and the family need reassurance that the symptom can be effectively managed at home without the need for activation of the emergency medical services or hospitalisation and that a nurse will be available at all times via telephone or to conduct a visit.

Nutrition and hydration at the end of life

Anorexia

Anorexia (loss of appetite) is distinct from anorexia nervosa (a serious mental disorder). Palliative care may be appropriate for a select group of patients with anorexia nervosa; however, this remains a contentious issue (Geppert, 2015). Anorexia and cachexia are common problems in the seriously ill, and there is a recognised condition, known as the cachexia–anorexia syndrome, that may develop in patients with cancer and some other palliative conditions (PCEG, 2010). The profound changes in the patient's appearance and a lack of interest in the socially important rituals of mealtime are particularly disturbing to families. The syndrome is characterised by disturbances in carbohydrate, protein and fat metabolism, endocrine dysfunction and anaemia. It is important to address anorexia earlier in the palliative episode as it reduces anxiety for both patient and family and significantly improves patients' morale and affects their energy levels (O'Connor & Récoché, 2012; Preedy, 2011). The approach to the problem varies depending on the patient's stage of illness, level of disability associated with the illness and desires.

Although causes of anorexia may be controlled for a period of time, progressive anorexia is an expected and natural part of the dying process. Anorexia may be related to or exacerbated by situational variables (e.g. the ability to have meals with the family versus eating alone in the 'sick room'), progression of the disease, treatment of the disease or psychological distress. The patient and the family should be instructed in strategies to manage the variables associated with anorexia. Table 12-2 summarises nursing measures and patient and family teaching for managing anorexia.

Use of pharmacological agents to stimulate appetite. A number of pharmacological agents are frequently used to stimulate appetite in anorexic patients. Commonly used medications for appetite stimulation include dexamethasone, cyproheptadine, megestrol acetate and dronabinol (PCEG, 2010). Although these agents may result in temporary weight gain, their use is not associated with an increase in lean body mass in terminally ill patients. Therapy should be tapered or discontinued after 4 to 8 weeks if there is no response (Wrede-Seaman, 2008).

Dexamethasone initially increases appetite and may provide short-term weight gain in some patients. It should be considered for those patients whose life expectancy is less than 6 weeks because the beneficial effects may be limited to the first few weeks of therapy and side effects increase over time (PCEG, 2010; Radbruch et al., 2010). However, therapy may need to be discontinued in patients with a longer life expectancy because after 3 to 4 weeks, corticosteroids interfere with the synthesis of muscle protein. Cyproheptadine may be used when corticosteroids are contraindicated, such as when the patient is diabetic. It promotes mild appetite increase but no appreciable weight gain.

Megestrol acetate produces temporary weight gain of primarily fatty tissue, with little effect on protein balance. Therapy should not be initiated if life expectancy is less than 30 days because of the time required to see any effect from this agent. With long-term use, megestrol acetate may have fewer side effects than dexamethasone. Dronabinol is a psychoactive compound found in cannabis that may be helpful in reducing nausea and vomiting, appetite loss, pain and anxiety, thereby improving food and fluid intake in some patients. However, in most patients, it is not as effective as other agents for appetite stimulation. Although dronabinol (a synthetic form of tetrahydrocannabinol [THC]) may have beneficial effects on appetite in patients with advanced cancer, it has not been shown to be more effective than megestrol. In addition, it produces undesirable central nervous system side effects (Radbruch et al., 2010; Suzuki et al., 2013).

Small amounts of alcohol before meals can help to stimulate appetite, add calories and have positive psychosocial benefits. Counselling for family members may also be indicated to help them come to terms with their loved ones' situation and to prevent them from force-feeding the patient.

Cachexia

Cachexia refers to severe muscle wasting and weight loss associated with illness. Although anorexia may exacerbate cachexia, it is not the primary cause. Cachexia is associated

TABLE 12-2 Measures for managing anorexia

Nursing interventions	Patient and family teaching tips
Initiate measures to ensure adequate dietary intake without adding stress to the patient at mealtimes.	Reduce the focus on 'balanced' meals; offer the same food as often as the patient desires it.
Assess the impact of medications (e.g. chemotherapy, antiretrovirals) or other therapies (radiation therapy, dialysis) that are being used to treat the underlying illness.	Increase the nutritional value of meals. For example, add dry milk powder to milk and use this fortified milk to prepare cream soups, milkshakes and gravies.
Administer and monitor effects of prescribed treatment of nausea, vomiting and delayed gastric emptying.	
Encourage the patient to eat when effects of medications have subsided.	Allow and encourage the patient to eat when hungry, regardless of usual mealtimes.
Assess and modify environment to eliminate unpleasant odours and other factors that cause nausea, vomiting and anorexia.	Eliminate or reduce noxious cooking odours, pet odours or other odours that may precipitate nausea, vomiting or anorexia.
Remove items that may reduce appetite (soiled tissues, bedpans, emesis basins, clutter).	Keep the patient's environment clean, uncluttered and comfortable.
Assess and manage anxiety and depression to the extent possible.	Make mealtime a shared experience away from the 'sick' room whenever possible.
	Reduce stress at mealtimes.
Position to enhance gastric emptying.	Avoid confrontations about the amount of food consumed.
	Reduce or eliminate routine weighing of the patient.
	Encourage the patient to eat in a sitting position; elevate the head of the patient's bed.
	Plan meals (food selection and portion size) that the patient desires.
Assess for constipation and/or intestinal obstruction.	Provide small frequent meals if they are easier for patient to eat.
Prevent and manage constipation on an ongoing basis, even when the patient's intake is minimal.	Ensure that the patient and the family understand that prevention of constipation is essential, even when the patient's intake is minimal.
Provide frequent mouth care, particularly following nourishment.	Encourage adequate fluid intake, dietary fibre and use of bowel program to prevent constipation.
Ensure that dentures fit properly.	Assist the patient to rinse after every meal. Avoid mouthwashes that contain alcohol or glycerine, which dry mucous membranes.
Administer and monitor effects of topical and systemic treatment of oropharyngeal pain.	Weight loss may cause dentures to loosen and cause irritation. Remove them to inspect the gums and to provide oral care.
	The patient's comfort may be enhanced if pain medications given on an as-needed basis for breakthrough pain are administered before mealtimes.

with changes in metabolism that include hypertriglyceridaemia, lipolysis and accelerated protein turnover caused by cytokines either released by tumours or in response to tumours (PCEG, 2010; Suzuki et al., 2013). These processes appear to be similar at the end stages of both cancer and some non-cancer illnesses, such as heart disease and dementia (Glaetzer et al., 2011). However, the pathophysiology of cachexia in life-limiting illness is not well understood. The severity of tissue wasting is greater in life-limiting illness than would be expected from reduced food intake alone, and typically increasing appetite or food intake does not reverse cachexia in the terminally ill.

Anorexia and cachexia differ from starvation (simple food deprivation) in several important ways. Appetite is lost early in the process, the body becomes catabolic in a dysfunctional way and supplementation by gastric feeding (tube feeding) or parenteral nutrition in advanced disease does not replenish lost lean body mass. At one time, it was believed that patients

with cancer with rapidly growing tumours developed cachexia because the tumour created an excessive nutritional demand and diverted nutrients from the rest of the body. Research links cytokines produced by the body in response to a tumour to a complex inflammatory immune response present in patients whose tumours have metastasised, leading to anorexia, weight loss and altered metabolism. An increase in cytokines occurs not only in cancer but also in AIDS and many other chronic diseases (Glaetzer et al., 2011).

Artificial nutrition and hydration in life-limiting illness

Along with breathing, eating and drinking are essential to survival throughout one's lifetime. As patients near the end of life, their bodies' nutritional needs change, their desire for food and fluid may diminish and they may no longer be able to use, eliminate or store nutrients and fluids adequately. Eating, feeding and sharing meals are important social activities in families and communities, and food preparation and

enjoyment are linked to happy memories, strong emotions and hopes for survival. For the patient with serious illness, food preparation and mealtimes often become battlegrounds where well-meaning family members argue, plead and cajole to encourage the ill person to eat. It is not unusual for seriously ill patients to lose their appetites entirely, to develop strong aversions for foods they have enjoyed in the past or to crave a particular food to the exclusion of all other foods.

Although nutritional supplementation may be an important part of the treatment plan in early or chronic illness, unintended weight loss and dehydration are expected sequelae of progressive illness. As illness progresses, patients, families and clinicians may believe that without artificial nutrition and hydration, the terminally ill patient will 'starve', causing profound suffering and hastened death. However, starvation should not be viewed as the failure to implant tubes for nutritional supplementation or hydration of terminally ill patients with irreversible progression of disease. Parenteral nutrition does not improve weight loss or survival in patients who are close to death; in fact, there are beneficial effects to withholding or withdrawing artificial nutrition and hydration, such as decreased urine output and incontinence, decreased gastric fluids and emesis, decreased pulmonary secretions and respiratory distress and decreased oedema (PCEG, 2010). Furthermore, in patients who are close to death, symptoms associated with dehydration such as dry mouth, confusion and diminished alertness are common and typically do not respond to artificial nutrition. Dry mouth can generally be managed through nursing measures such as mouth care and environmental changes with medications to diminish confusion.

As the patient approaches the end of life, families and healthcare providers should offer the patient what they desire and can most easily tolerate. Nurses should instruct the family how to separate feeding from caring by demonstrating love, sharing and caring by being with their significant other in other ways. Preoccupation with appetite, feeding and weight loss diverts energy and time that the patient and the family could use in other meaningful activities. The following are tips to promote nutrition for the terminally ill patient:

- Offer small portions of favourite foods.
- Do not be overly concerned about a balanced diet.
- Cool foods may be better tolerated than hot foods.
- Offer cheese, eggs, peanut butter, mild fish, chicken or turkey. Red meat (especially beef) may taste bitter and unpleasant.
- Add milkshakes, instant breakfast drinks or other liquid supplements.
- Add dry milk powder to milkshakes and cream soups to increase protein and kilojoule content.
- Place nutritious foods at the bedside (fruit juices and milkshakes in insulated drink containers with straws).
- Schedule meals when family members can be present to provide company and stimulation.
- Avoid arguments at mealtime.
- Assist the patient to maintain a schedule of oral care. Rinse the mouth after each meal or snack. Avoid mouthwashes

that contain alcohol. Use a soft toothbrush. Treat ulcers or lesions. Make sure dentures fit well.

- Treat pain and other symptoms.
- Offer ice chips made from frozen fruit juices.
- Allow the patient to refuse foods and fluids.

Delirium

Many patients may remain alert, arousable and able to communicate until very close to death. Others may sleep for long intervals and awaken only intermittently, with eventual somnolence until death. Delirium refers to concurrent disturbances in level of consciousness, psychomotor behaviour, memory, thinking, attention and sleep-wake cycle (Bush et al., 2014a; Glaetzer et al., 2011). In some patients, a period of agitated delirium precedes death, sometimes causing families to be hopeful that suddenly active patients may be getting better. Family members may interpret agitated behaviour, for example, purposeless repetitive movements, moaning or facial grimacing to be an indication of pain which was previously well controlled (Bush et al., 2014a, 2014b). Delirium at the end of life, otherwise known as restlessness, is considered more of a syndrome than a symptom, as it overlaps delirium and cerebral irritability and often manifests as agitation, restlessness, distressing vocalisation and moaning. Delirium associated with end of life tends to be multifactorial and is exacerbated by the progressive shutdown of multiple body systems (Bush et al., 2014a, 2014b). Confusion may be related to underlying treatable conditions such as medication side effects or interactions, cytotoxic chemotherapy agents, radiation therapy to the brain, pain or discomfort, hypoxia or dyspnoea, a full bladder or impacted stool. In patients with cancer, confusion may be secondary to brain metastases. Delirium may also be related to metabolic changes, infection, organ failure, the presence of any central nervous system disease or withdrawal from alcohol or benzodiazepines (PCEG, 2010).

The patient with delirium may become hypoactive or hyperactive, restless, irritable and fearful. Sleep deprivation and hallucinations may occur. If treatment of the underlying factors contributing to these symptoms brings no relief, a combination of pharmacological intervention with neuroleptics or benzodiazepines may be effective in decreasing distressing symptoms. Haloperidol may reduce hallucinations and agitation. Benzodiazepines (e.g. lorazepam) can reduce anxiety but will not clear the sensorium and may contribute to worsening cognitive impairment if used alone. For those infrequently faced with the management of delirium at the end of life, it can be personally and professionally challenging (Bush et al., 2014a, 2014b). Determining whether or not end-of-life delirium is present rests heavily on excluding other, potentially reversible causes of the manifestations; therefore, comprehensive assessment is crucial. Careful recording and reporting of assessments, care provided and response to any interventions is also important for tracking changes in patient behaviour and condition over time. Apart from identifying the underlying causes of delirium, nursing interventions are aimed at acknowledging the family's distress over its

occurrence, reassuring them about what is normal, teaching the family how to interact with and ensure safety for the patient with delirium and monitoring the effects of medications used to treat severe agitation, paranoia or fear. Spiritual intervention, music therapy, gentle massage and therapeutic touch may provide some relief. Reducing environmental stimuli, avoiding harsh lighting or very dim lighting (which may produce disturbing shadows), the presence of familiar faces, gentle reorientation and reassurance are also helpful. Disorientation, confusion and agitation associated with delirium place patients at higher risk of falls and accidents, so proactive measures, such as beds which can be lowered to the floor, removal of obstacles and the use of monitors or alarms may assist in risk minimisation.

Depression

Clinical depression should not be accepted as an inevitable consequence of dying, nor should it be confused with sadness and anticipatory grieving, which are normal reactions to the losses associated with impending death. Emotional and spiritual support and control of disturbing physical symptoms are appropriate interventions for situational depression associated with life-limiting illness. Researchers have linked the psychological effects of cancer pain to suicidal thoughts and, less frequently, to carrying out a planned suicide (Robson et al., 2010). Although depression is not uncommon, it should not be regarded as inevitable. Depression and thoughts of self-harm in palliative care patients may lead to unnecessary psychological distress and be a factor in reduced survival (Lloyd-Williams et al., 2014). Patients with advanced disease, a life-limiting diagnosis, older age, poorly managed symptoms, lack of social support, self-concept disturbance, a history of substance abuse, existential distress, difficulty in expressing emotions and a personal or family history of depression are at higher risk of developing depressive symptoms (Esper, 2007). Patients and their families must be given space and time to experience sadness and to grieve, but patients should not have to endure untreated depression at the end of their lives. An effective combined approach to clinical depression includes relief of physical symptoms, counselling and attention to emotional and spiritual distress and pharmacological intervention with psychostimulants, selective serotonin reuptake inhibitors and tricyclic antidepressants (Lorenz et al., 2008; PCEG, 2010). If patients do not respond, then referral to a psychiatrist may be necessary.

Palliative sedation at the end of life

When symptoms are refractory or unresponsive to traditional forms of treatment, a patient may require **sedation** to a level that decreases consciousness. This is an area where prudent practice is required to avoid ethical and medicolegal problems because some view terminal sedation as thinly-veiled doctor-assisted suicide or euthanasia (Cherny & Radbruch, 2009; Papavasiliou et al., 2013). Sedation is distinguished from euthanasia or doctor-assisted suicide in that the intent of sedation is to palliate the symptoms rather than hasten the

patient's death. Sedation is most commonly used when the patient exhibits intractable pain, dyspnoea, seizures or delirium. It is generally considered appropriate in only the most difficult cases. Before implementing sedation, the care team should assess for the presence of underlying and treatable causes of suffering, such as depression or spiritual distress. Finally, patients and families should be fully informed about the use of this treatment and alternatives.

Nursing care of the patient who is close to death

Providing care to the patient who is close to death and being present at the time of death can be one of the most rewarding experiences a nurse can have. Patients and their families are understandably fearful of the unknown, and the approach of death may prompt new concerns or cause previous fears or issues to resurface. It has often been said that as we age and as we approach death, we do not become different people, just more like ourselves. Families who have always had difficulty communicating or in which there are old resentments and hurts may experience heightened difficulty as their significant other nears death. In contrast, the time at the end of life can also afford the family the opportunity to resolve old hurts and learn new ways of being a family. Regardless of the setting, dying patients can be made comfortable, space can be made for their significant others to remain present when they wish and the opportunity to experience growth and healing can be facilitated by skilled practitioners. Likewise, regardless of setting, patients' and families' apprehension surrounding the time of death may be diminished if they know what to expect and how to respond as death approaches.

Expected physiological changes when the patient is close to death

Observable, expected changes in the body take place as the patient approaches death and organ systems begin to fail. Nursing care measures aimed at patient comfort should be continued: pain medications (administered rectally, sublingually, subcutaneously or intravenously), turning, mouth care, eye care, positioning to facilitate draining of secretions and measures to protect the skin from incontinence should be continued. The nurse should consult with the doctor about discontinuing measures that no longer contribute to patient comfort such as drawing blood, administering tube feedings, suctioning (in most cases) and invasive monitoring. The nurse should prepare the family for the normal, expected changes that accompany the period immediately preceding death. Although the exact time of death cannot be predicted, it is often possible to identify when a patient is very close to death. Palliative care providers frequently offer written information for families so that they know what to expect and what to do as death nears (see Chart 12-10). If they have been prepared for the time of death, families are less likely to panic and will be better able to be with their significant other in a meaningful way. Noisy, gurgling breathing or moaning is

CHART 12-10 Educating the family: Signs of approaching death

The person shows less interest in eating and drinking. For many patients, refusal of food is an indication that they are ready to die. Fluid intake may be limited to that which will keep their mouths from feeling too dry.

- *What you can do:* Offer, but do not force, fluids and medication. Sometimes pain or other symptoms that have required medication in the past may no longer be present. For most patients, pain medications are still needed, and they can be provided by concentrated oral solutions placed under the tongue or by rectal suppository.

Urinary output may decrease in amount and frequency.

- *What you can do:* No response is needed unless the patient expresses a desire to urinate and cannot. Call the palliative care nurse for advice if you are not sure.

As the body weakens, the patient will sleep more and begin to detach from the environment. He or she may refuse your attempts to provide comfort.

- *What you can do:* Allow your loved one to sleep. You may wish to sit with him or her, play soft music or hold hands. Your loved one's withdrawal is normal and is not a rejection of your love.

Mental confusion may become apparent. This occurs because less oxygen is available to supply the brain. The patient may report strange dreams or visions.

- *What you can do:* As he or she awakens from sleep, remind him or her of the day and time, where he or she is and who is present. This is best done in a casual, conversational way.

Vision and hearing may become somewhat impaired, and speech may be difficult to understand.

- *What you can do:* Speak clearly but no more loudly than necessary. Keep the room as light as the patient wishes, even at night.
- Carry on all conversations as if they can be heard, because hearing may be the last of the senses to cease functioning.
- Many patients are able to talk until minutes before death and are reassured by the exchange of a few words with a loved one.

Secretions may collect in the back of the throat and rattle or gurgle as the patient breathes through the mouth. He or she may try to cough, and his or her mouth may become dry and encrusted with secretions.

- *What you can do:* If the patient is trying to cough up secretions and is experiencing choking or vomiting, call the palliative care nurse for assistance.
- Secretions may drain from the mouth if you place the patient on his or her side and provide support with pillows.

- Cleansing the mouth with moistened mouth swabs will help to relieve the dryness that occurs with mouth breathing.
- Offer water in small amounts to keep the mouth moist. A straw with one finger placed over the end can be used to transfer sips of water to the patient's mouth.

Breathing may become irregular with periods of no breathing (apnoea). The patient may be working very hard to breathe and may make a moaning sound with each breath. As the time of death nears, the breathing remains irregular and may become more shallow and mechanical.

- *What you can do:* Raising the head of the bed may help the patient to breathe more easily. The moaning sound does not mean that the patient is in pain or other distress; it is the sound of air passing over very relaxed vocal cords.

As the oxygen supply to the brain decreases, the patient may become restless. It is not unusual to pull at the bed linens, to have visual hallucinations or even to try to get out of bed at this point.

- *What you can do:* Reassure the patient in a calm voice that you are there. Prevent him or her from falling by trying to get out of bed. Soft music or a back rub may be soothing.

The patient may feel hot one moment and cold the next as the body loses its ability to control temperature. As circulation slows, the arms and legs may become cool and bluish. The underside of the body may darken. It may be difficult to feel a pulse at the wrist.

- *What you can do:* Provide and remove blankets as needed. Avoid using electric blankets, which may cause burns because the patient cannot tell you if he or she is too warm.
- Sponge the patient's head with a cool cloth if this provides comfort.

Loss of bladder and bowel control may occur around the time of death.

- *What you can do:* Protect the mattress with waterproof padding, and change the padding as needed to keep the patient comfortable.

As people approach death, many times they report seeing gardens, libraries, or family or friends who have died. They may ask you to pack their bags and find tickets or a passport. Sometimes they may become insistent and attempt to do these chores themselves. They may try getting out of bed (even if they have been confined to bed for a long time) so that they can 'leave'.

- *What you can do:* Reassure the patient that it is all right; he or she can 'go' without getting out of bed. Stay close, share stories and be present.

Used with permission from the Hospice of Philadelphia. Hospice and Palliative Nurses Association. (2011). *HPNA position statement: Legalization of assisted suicide*. Available at www.hpna.org/DisplayPage.aspx?Title=Position%20Statements.

generally most distressing to the family. In most cases, the sounds of breathing at the end of life are related to oropharyngeal relaxation, loss of gag reflex and diminished awareness. Family members may have difficulty believing that the patient is not in pain or that his or her breathing could not be improved by suctioning secretions. Patient

positioning and family reassurance are the most helpful responses to these symptoms.

Noisy breathing or death rattle

Death rattle is a term to describe noisy respirations which occur when a patient is in the last few days or hours of life

(Glaetzer et al., 2011; Twomey & Dowling, 2013). During end-stage care, a patient usually becomes weaker, their level of consciousness decreases and the cough/gag reflexes diminish or are absent. Oral, gastric and/or pulmonary secretions accumulate, and as air passes over the secretions, a gurgling or rattly sound is produced. Most patients are unconscious and not distressed by this symptom but it can be very distressing for family members (Shimizu et al., 2014). Nursing care involves using simple language to explain to family members the reason for the noisy respirations and also reassurance that the patient is not suffering. Suctioning may stimulate the production of additional secretions and is not generally recommended. Suctioning may also be traumatic if the patient is still responsive. Mouth care and gentle removal of secretions is advocated and this is something that family members can be taught to do. Involving families in care may be beneficial but only if they are willing to do so. The patient should be nursed from side to side and in a semiupright position. Repositioning should be performed every 3 to 4 hours.

Medications may be administered (see Table 12-3); however, the efficacy of one particular drug over another is unclear. Medications may not be as effective when secretions are already present but they may stop the production of further secretions. Drugs for noisy secretions may be more beneficial if given early; therefore, prompt reporting of noisy secretions by nurses is essential (Eastern Metropolitan Region Palliative Care Consortium, 2013; Glaetzer et al., 2011).

TABLE 12-3 Pharmacological management of excess oral/respiratory secretions when death is imminent

Medication	Dose
For a conscious patient Glycopyrrolate OR Hyoscyamine butylbromide	0.2 mg–0.4 mg SC as single dose, followed by 0.6 mg–1.2 mg/24 hours SC by continuous infusion (glycopyrrolate does not cross the blood–brain barrier, so it will not add to delirium). 20 mg SC 4 hourly, or 60–80 mg/24 h SC, by continuous infusion and titrate to effect (to a maximum of 120 mg/24 h).
For an unconscious patient Atropine OR Hyoscine hydrobromide	0.4–0.6 mg SC, every 4–6 h to a maximum of 2.4 mg/24 h (atropine readily crosses the blood–brain barrier and prolonged use can worsen the ‘anticholinergic load’ and hence delirium). 0.4 mg SC, every 4 h or 0.8–2.4 mg/d SC, by continuous infusion (can cause confusion and sedation; sedation may be beneficial in some circumstances).

SC, subcutaneously.

From Palliative Care Expert Group. (2010). *Therapeutic guidelines: Palliative care. Version 3* (pp. 272–273). Melbourne: Therapeutic Guidelines Limited. Available at www.tg.org.au/index.php?sectionid=47.

The death vigil

Although every death is unique, it is often possible for the experienced clinician to ascertain that the patient is ‘actively’ or imminently dying and to prepare the family in the final days or hours leading to death. As death nears, the patient may withdraw, sleep for longer intervals or become somnolent. Death is generally preceded by gradual cessation of bodily functions, increased intervals between respirations, a weakened and irregular pulse, diminished blood pressure and skin colour changes or mottling. The family should be encouraged to be with the patient, to speak and reassure him or her of their presence, to stroke or touch him or her or to lie alongside him or her (even in the hospital or residential care facility) if they are comfortable with this degree of closeness and can do so without causing discomfort to the patient.

Family members may have gone to great lengths to ensure that their significant other will not die alone. However, despite the best intentions and efforts of families and clinicians, the patient’s death may occur at a time when no one is present. In any setting, it is unrealistic for family members to be at the patient’s bedside 24 hours a day, and it is not unusual for patients to die when the family has stepped away from the bedside just briefly. Experienced palliative clinicians have observed and reported that some patients appear to ‘wait’ until family members are away from the bedside to die, perhaps to spare their significant others the pain of being present at the time of death. If a patient dies while family members are away from the bedside, they may express feelings of guilt and profound grief and may need emotional support.

After-death care

For the patient who has received adequate management of symptoms and for the family who has received preparation and support, the actual time of death is commonly peaceful and occurs without struggle. The nurse may or may not be present at the time of the patient’s death. The person who can certify death is determined by each state and may differ according to the jurisdiction. For example, in Victoria, nurses and paramedics are permitted to verify death, but certification is still required by a licensed medical practitioner for legal purposes. Similarly, in NSW, the attending doctor makes the pronouncement of death and signs the death certificate, but in circumstances when the doctor is not present and death is expected, death may be declared by the nurse. The determination of death is made through a physical examination that includes auscultation for the absence of breathing and heart sounds. Home-based palliative care services will have policies and procedures to guide the nurse’s actions during a home visit.

Immediately upon cessation of vital functions, the body will begin to change. The body will become dusky or bluish, waxen-like, and cool, blood will darken and pool in dependent areas of the body (such as the back and sacrum if the body is in a supine position) and urine and stool may be evacuated.

Immediately following the death, the family should be allowed and encouraged to spend time with the deceased.

Normal responses of family members at the time of death vary widely and range from quiet expressions of grief to overt expressions that include wailing and prostration.

Families' desires for privacy during their time with the deceased should be honoured. Family members may wish to independently manage or assist with care of the body after death. If the death occurs in a hospital or residential care facility, the nurse follows the facility's procedure for preparation of the body and transportation to the funeral home. However, the family's request to remain with the deceased, to wait until other family members arrive before the body is moved and to perform after-death rituals should be honoured. When an expected death occurs at home, the body is often transported directly to the funeral home by the funeral director.

Grief, mourning and bereavement

A wide range of feelings and behaviours are normal, adaptive and healthy reactions to the loss of a significant other. **Grief** refers to the personal feelings that accompany an anticipated or actual loss. **Mourning** reflects the individual, family, group and cultural expressions of grief and associated behaviours. **Bereavement** refers to the period of time during which mourning takes place. Both grief reactions and mourning behaviours change over time as the individual learns to live with the loss. Although the pain of the loss may be tempered by the passage of time, recent conceptualisations of loss as an ongoing developmental process maintain that time does not heal the bereaved individual completely; that is, the bereaved

do not get over a loss entirely, nor do they return to who they were before the loss. Rather, they develop a new sense of who they are and where they fit in a world that has changed dramatically and permanently.

Anticipatory grief and mourning

Denial, sadness, anger, fear and anxiety are normal grief reactions in the individual with life-limiting illness and those close to him or her. Kübler-Ross (1969) described five common emotional reactions to dying that are applicable to the experience of any loss (see Table 12-4). Not every patient or family member experiences every stage; many patients never reach a stage of acceptance, and patients and families fluctuate on a sometimes daily basis in their emotional responses. Furthermore, although impending loss stresses the patient, people who are close to him or her and the functioning of the family unit, awareness of dying also provides a unique opportunity for family members to reminisce, resolve relationships, plan for the future and say goodbye.

Individual and family coping with the anticipation of death is complicated by the varied and conflicting trajectories that grief and mourning may assume in the family. For example, while the patient may be experiencing sadness while contemplating role changes that have been brought about by the illness, the patient's spouse or partner may be expressing or containing feelings of anger about the current changes in role and impending loss of the relationship; others in the family may be engaged in denial, fear or profound sadness and withdrawal. Although each of these behaviours is normal, tension

TABLE 12-4 Kübler-Ross's five stages of grief

Stage	Nursing implications
Denial: 'This cannot be true.' Feelings of isolation. May search for another healthcare professional who will give a more favourable opinion. May seek unproven therapies.	Denial can be an adaptive response, providing a buffer after bad news. It allows time to mobilise defences but can be maladaptive when it prevents the patient or the family from seeking help or when denial behaviours cause more pain or distress than the illness or interfere with everyday functions. Nurses should assess the patient's and family's coping style, information needs and understanding of the illness and treatment to establish a basis for empathetic listening, education and emotional support. Rather than confronting the patient with information that they are not ready to hear, the nurse can encourage him or her to share fears and concerns. Open-ended questions or statements such as 'Tell me more about how you are coping with this new information about your illness' can provide a springboard for expression of concerns.
Anger: 'Why me?' Feelings of rage, resentment or envy directed at God, healthcare professionals, family, others.	Anger can be very isolating, and loved ones or clinicians may withdraw. Nurses should allow the patient and the family to express anger, treating them with understanding, respect and knowledge that the root of the anger is grief over impending loss.
Bargaining: 'I just want to see my grandchild's birth, then I'll be ready....' Patient and/or family plead for more time to reach an important goal. Promises are sometimes made with God.	Terminally ill patients are sometimes able to outlive prognoses and achieve some future goal. Nurses should be patient, allow expression of feelings and support realistic and positive hope.
Depression: 'I just don't know how my kids are going to get along after I'm gone.' Sadness, grief, mourning for impending losses.	Normal and adaptive response. Clinical depression should be assessed and treated when present. Nurses should encourage the patient and the family to fully express their sadness. Insincere reassurance or encouragement of unrealistic hopes should be avoided.
Acceptance: 'I've lived a good life, and I have no regrets.' Patient and/or family are neither angry nor depressed.	The patient may withdraw as his or her circle of interest diminishes. The family may feel rejected by the patient. Nurses need to support the family's expression of emotions and encourage them to continue to be present for the patient.

CHART 12-11 ASSESSMENT**Assessing for anticipatory mourning in the family facing life-threatening illness****Family constellation**

- Identify the members who constitute the patient's family.
 - Who is important to the patient?
- Identify roles and relationships among the family members:
 - Who is the primary caregiver?
 - By what authority is this person the primary caregiver?

Cohesion and boundaries

- How autonomous/interdependent are family members?
 - Degree of involvement with each other as individuals and as a family
 - Degree of bonding between family members
 - Degree of 'teamwork' in the family
 - Degree of reliance on individual family members for specific tasks/roles
- How do family members differ in:
 - Personality?
 - Worldview?
 - Priorities?

- What are the implicit and explicit expectations or 'rules' for behaviour within the family?

Flexibility and adaptability

- What is the family's ability to integrate new information?
- How does the family manage change?
- How able are the family members to assume new roles and responsibilities?

Communication

- What is the style of communication in the family, in terms of:
 - Openness?
 - Directness?
 - Clarity?
- What are the constraints on communication?
- What topics are avoided?

may arise when one or more family members perceive that others are less caring, too emotional or detached.

The nurse should assess the family dynamics and intervene in a manner that supports and enhances cohesion of the family unit. Parameters for assessing the family facing life-threatening illness are identified in Chart 12-11. Acknowledging and expressing feelings, continuing to interact with the patient in meaningful ways and planning for death and bereavement are adaptive family behaviours. Professional support provided by grief counsellors in the community, at local hospitals, in residential care facilities or associated with a palliative care program can help both the patient and the family to sort out and acknowledge feelings and make the end of life as meaningful as possible.

Grief and mourning after death

When a significant other dies, the family members enter a new phase of grief and mourning as they begin to accept the loss, feel the pain of permanent separation and prepare to live a life without the deceased. Even if the person died after a long illness, preparatory grief experienced during the illness will not preclude the grief and mourning that follow the death. With a death after a long or difficult illness, family members may experience conflicting feelings of relief that the significant other's suffering has ended, compounded by guilt and grief related to unresolved issues or the circumstances of death. Grief work may be especially difficult if the patient's death was painful, prolonged, accompanied by unwanted interventions or unattended. Families that had no preparation or support during the period of imminence and death may have a more difficult time with painful memories.

Although some family members may experience prolonged or complicated mourning, most grief reactions fall

within a 'normal' range. The feelings are often profound, but the bereaved individual eventually reconciles the loss and finds a way to re-engage with his or her life. Grief and mourning are affected by individual characteristics, coping skills and experiences with illness and death; the nature of the relationship to the deceased; factors surrounding the illness and the death; family dynamics; social support; and cultural expectations and norms.

After-death rituals, including preparation of the body, funeral practices and burial rituals, are socially and culturally significant ways that members of a family begin to accept the reality and finality of death. Preplanning of funerals is becoming increasingly common, and palliative care and hospice professionals assist families to make plans for death, often involving the patient who may wish to take an active planning role. Preplanning the funeral relieves the family of the decision in the intensely emotional period following a death. Uncomplicated grief and mourning are characterised by sadness, anger, guilt, fear and distress as appropriate to culture and context; numbness; physical sensations such as hollowness in the stomach and chest tightness, weakness and lack of energy; cognitions that include preoccupation with the loss and a sense of the deceased as still present; and behaviours such as crying, anxiety, agitation and restlessness or inactivity and withdrawal (PCEG, 2010).

In general, the period of mourning is an adaptive response to loss during which the mourner comes to accept the loss as real and permanent, acknowledges and experiences the painful emotions that accompany the loss, experiences life without the deceased, overcomes impediments to adjustment and finds a new way of living in a world without the significant other. Particularly immediately following the death, the mourner begins to recognise the reality and permanence of the loss by talking about the deceased and

retelling the story of the illness and death. Societal norms are frequently at odds with the normal grieving processes of individuals, where time excused from work obligations is typically measured in days and mourners are often expected to get over the loss quickly and get on with life.

The acute phase of grief lasts for around 6 weeks and during this time, supportive care is all that is usually required. Most organisations which provide palliative care either employ or have access to counsellors who can provide specialist support to family members following their loss. In reality, the work of grief and mourning takes time, and avoiding grief work following the death often leads to long-term adjustment difficulties.

Although many individuals complete the work of mourning with the informal support of family and friends, many find that talking with others who have had a similar experience, such as in formal support groups, normalises the feelings and experiences and provides a framework for learning new skills to cope with the loss and create a new life (Bellamy et al., 2014). Bereavement support groups are often sponsored by hospitals, hospices and other community organisations. Palliative care providers, particularly community-based organisations, maintain contact with families for a period of 12 months after bereavement and offer opportunities for families to reflect on their loved one's life and their loss through such events as remembrance services. Groups for parents who have lost a child, children who have lost a parent, widows, widowers and gay men and lesbians who have lost a life partner are some examples of specialised support groups. Nursing interventions for those experiencing grief and mourning are identified in Chart 12-12.

Complicated or prolonged grief and mourning

Complicated grief and prolonged grief are terms that are often used synonymously (Jordan & Litz, 2014).

Complicated/prolonged grief and mourning are characterised by prolonged feelings of sadness, general worthlessness or hopelessness that persist long after the death, prolonged symptoms that interfere with activities of daily living (anorexia, insomnia, fatigue, panic) or self-destructive behaviours such as alcohol or substance abuse and suicidal thoughts or attempts. Evidence suggests that only a minority of people will require specialist bereavement support services to manage grief (Hall et al., 2012; Morris & Block, 2015). Bereavement support standards for specialist palliative care services provide guidance for staff when complex grief is an issue (Hall et al., 2012). There are a variety of resources and assessment tools used to assist health professionals to identify individuals at risk (Caresearch, 2015b; Hall et al., 2012). The predeath period has been shown to be the best opportunity for staff to assess caregivers who are at risk of complicated bereavement (Sealey et al., 2015). Nurses often have the most contact with family members and are well placed to identify individuals at risk of complicated bereavement. Assessment, documentation and referral to appropriate resources, including other members of the multidisciplinary team, are an important role that nurses have in supporting

CHART 12-12 Nursing interventions for grief and mourning

Support the expression of feelings

- Encourage the telling of the story using open-ended statements or questions (e.g. 'Tell me about your husband').
- Assist the mourner to find an outlet for his or her feelings: talking, attending a support group, keeping a journal, finding a safe outlet for angry feelings (writing letters that will not be mailed, physical activity)
- Assess emotional affect and reinforce the normalcy of feelings.
- Assess for guilt and regrets.
 - Are you especially troubled by a certain memory or thought?
 - How do you manage those memories?

Assess for the presence of social support

- Do you have someone to whom you can talk about your husband?
- Can I help you to find someone you can talk to?

Assess coping skills

- How are you managing day to day?
- Have you experienced other losses? How did you manage those?
- Are there things you are having trouble doing?
- Do you have/need help with specific tasks?

Assess for signs of complicated grief and mourning and offer professional referral

caregivers. Complicated/prolonged grief and mourning may require professional assessment and can be treated with pharmacological and psychological interventions.

CLINICAL REASONING CHALLENGE

You are making follow-up calls to the primary carers (family members) for all the patients who have died in the past 3 months in the hospital unit where you are the clinical nurse consultant. What questions could you ask to screen for complicated grief and bereavement? What activities or strategies would you consider to help families to deal with their loss (before and after the death)? What is the evidence for your selection of those activities and strategies? What resources are available in the community? What bereavement services are indicated for the staff? What would you suggest to a staff member who continues to have problems coping with the death of his or her patients?

Coping with death and dying: Professional carer issues

Whether practising in the trauma centre, intensive care unit or other acute care setting, home care, hospice, residential care or the many locations where patients and their families receive ambulatory services, nurses are closely involved with complex and emotionally laden issues surrounding loss of life. To be most effective and satisfied with the care they

provide, nurses need to attend to their own emotional responses to the losses they witness every day (Doka, 2014). Studies have identified the need for staff support, particularly in relation to acknowledging suffering in patients, families and colleagues. Some of the strategies offered by various authors ranged from empowerment of health professionals through education and personal development and introduction of formal staff support structures. Well before the nurse exhibits symptoms of stress or burnout, they should acknowledge the difficulty of coping with others' pain on a daily basis and put healthy practices in place that will guard against emotional exhaustion. In hospice and palliative care settings, where death, grief and loss are expected outcomes of patient care, interdisciplinary colleagues rely on each other for support, using meeting time to express frustration, sadness, anger and other emotions; to learn coping skills from each other; and to speak about how they were affected by the lives of those patients who have died. In many settings, staff members organise or attend memorial services to support families and other carers, who find comfort in joining each other to remember and celebrate the lives of patients. Finally, healthy personal habits, including diet, exercise, stress reduction activities (such as dance, yoga, t'ai chi, meditation) and sleep, will help reduce the detrimental effects of stress.

CLINICAL REASONING EXERCISES

1. **ebp** Your patient, aged 70 years, has metastatic prostate cancer and is receiving home palliative care. In the past, he has received transfusions of packed red blood cells to treat anaemia associated with bone marrow involvement but obtained only temporary benefit. The patient's wife has asked that her husband's haemoglobin continue to be checked weekly because she is concerned about his increasing weakness and exertional dyspnoea. The interdisciplinary team is meeting to discuss the patient's treatment plan. The team consensus is that he is unlikely to live more than a few days or weeks. What additional assessment data is needed to determine the wishes and expectations of the patient and of the wife? What are the team's options for intervention? What evidence-based literature is associated with each option?
2. You are conducting your first community care visit to an 88-year-old woman who has been hospitalised with heart failure three times in the last 4 months. She is short of breath, although she uses oxygen continuously. She is confined to bed, is incontinent and has a stage III pressure ulcer on her coccyx. She is not interested in eating and has lost 18 kg in the last 4 months. She is becoming progressively weaker. Her husband, also aged 88 years, has limited mobility due to arthritis. He has a history of colon cancer and has had a colostomy for the last 10 years. Although he tries to take care of his wife, it is becoming increasingly difficult for him to do so. They have been married for almost 70 years and are very devoted to each other. What assessments would you carry out and what strategies would you implement to (1) relieve some of the patient's symptoms and discomfort, (2) assist her husband in management of her care and (3) prepare both of them for her inevitable death?
3. **ebp** You are the new unit manager on a hospice unit that is part of a long-term care facility. While reviewing documented nursing assessments, you note that pain intensity scores (0 to 10) are recorded for some residents, although for others, a mix of methods is used to evaluate pain. What is the evidence base for pain assessment in palliative care? Identify the criteria used to evaluate the strength of the evidence for this practice. How will you evaluate the implementation of a new tool or tools?
4. **pcq** You are caring for a 68-year-old man with end-stage heart failure in a hospital-based palliative care unit. You observe that he has peripheral oedema and cachexia. He reports dyspnoea at rest, profound fatigue and activity intolerance. He tells you that he would like to return home, but his wife becomes very anxious when he has pain or shortness of breath, causing him to become anxious as well. What priority assessments would you conduct? What specific information should you include first in a discussion with this man and his wife? What type of information and in what format would be appropriate for this man and his wife?

ONLINE RESOURCES

For an extensive range of additional resources to enhance teaching and learning and to facilitate understanding of this chapter, please see the text's accompanying website located on **thePoint**® at <http://thepoint.lww.com>.

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RESOURCES

- Australian and New Zealand Society of Palliative Medicine: www.anzspm.org.au
- Australian Centre for Grief and Bereavement: www.grief.org.au
- Best Practice Advocacy Centre New Zealand (bpac^{nz}): www.bpac.org.nz/
- CareSearch Palliative Care Knowledge Network: www.caresearch.com.au/Caresearch/Default.aspx
- Caring Connections (a program of the National Hospice and Palliative Care Organization): www.caringinfo.org
- Clinical Oncological Society of Australia: www.cosa.org.au
- Commonwealth Department of Health and Ageing: www.health.gov.au
- Hospice Education Institute: www.hospiceworld.org
- Hospice New Zealand: www.hospice.org.nz
- International Association for Hospice & Palliative Care: www.hospicecare.com
- National Association for Home Care & Hospice: www.nahc.org/haa
- National Association for Loss & Grief (Australia): www.nalag.org.au/index.htm
- National Association for Loss & Grief (NZ): www.nalag.org.nz
- National Consensus Project for Quality Palliative Care (national guidelines): www.nationalconsensusproject.org
- National Hospice and Palliative Care Organization: www.nhpco.org
- National Palliative Care Research Center: www.npcrc.org
- New Zealand Ministry of Health: www.moh.govt.nz
- Palliative Care Australia: www.palliativecare.org.au
- Palliative Care Curriculum for Undergraduates (PCC4U): www.pcc4u.org/
- Palliative Care Nurses Australia: www.pcna.org.au
- Palliative Care Nurses New Zealand: www.pcnz.co.nz
- Skylight New Zealand (helping children with loss and grief): www.skylight.org.nz
- Very Special Kids: www.vsk.org.au
- Virtual Medical Centre (cancer): www.virtualmedicalcentre.com/cancer
- Worldwide Palliative Care Alliance: www.thewpca.org