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ESSENTIALS Palliative care shifts the focus of care from managing the underlying pathophysiological processes to one that looks at the individual and the impact of life-threatening illness on them and those important to them. It aims to prevent and relieve suffering by means of early identification, assessment, and treatment of pain and other problems, physical, psychosocial, and spiritual. It focuses on interventions which might improve an individual's quality of life rather than alter the underlying disease process, and routinely extends support to those important to the individual both during that individual's lifetime and into bereavement. Challenges to the provision of effective palliative care include prognostic uncertainty, the necessity for engaging in difficult conversations, and the need to deal with a variety of ethical issues. However, palliative care exemplifies all the principles that underpin good medical care, and is everybody's business because we are all on the same journey and we all matter because of who we are, not what we do. What is palliative care? Palliative care is relevant to almost every aspect of clinical practice, dealing as it does with the end stages of all disease processes. Palliative care shifts the focus of care from managing the underlying pathophysiological processes, with emphasis on controlling actual or potential damage, to one that looks at the individual and the impact of their illnesses on them and those important to them, as illustrated in the case study next. According to the World Health Organization (WHO) (2011), palliative care is defined as: . . . an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of an illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as

chemo- therapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. Reprinted from WHO Definition of Palliative Care

(<http://www.who.int/cancer/palliative/definition/en/>),

© WHO 2017. The art of caring for those approaching the end of their lives has a long history, much of which originates from caring institutions established by different world religions over the centuries. Building on that experience, most accept that the 'modern hospice movement' was founded by Dame Cecily Saunders in the United Kingdom in the mid-20th century. While there is considerable qualitative evidence that a caring approach embracing psychological, psychosocial, and spiritual support is highly effective and valued by patients and families, considerable gaps remain in our understanding of the physiology of the end stages of disease processes and in the evidence base for the interventions currently on offer. This, combined with the often complex interactions between the physical, emotional, and psychological elements of each patient's lived experience, makes the palliative care approach both challenging and fascinating (Box 7.1.1). What is a palliative care approach? Individuals with progressive life-limiting illnesses face similar challenges, whether their illness journey is one of slow decline

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624 Section 7 Pain and palliative care over years, or an apparent precipitous deterioration in health over a few weeks. For all there will be a progressive loss of function and a variable burden of symptoms combined with emotional, psychological, and spiritual distress as illustrated in our case study. A palliative care approach acknowledges the individual's lived experience of the situation they are in and aims to work in partnership with the individual to find ways to manage what is important for them. For P in our case study, being able to spend time at home with family was important as was writing letters for his grandchildren. Palliative care routinely extends support to those important to the individual both during that individual's lifetime and into bereavement. Hearing and acknowledging the thoughts and feelings of P's wife were an important aspect of the case. Palliative care focuses on interventions which might improve an individual's quality of life rather than alter the underlying disease process. As such it includes provision of:

- accurate holistic assessment of patients including their psychological, social, spiritual, and practical needs
- accurate and realistic information for patients and carers about their condition and the choices they have around next steps, with 'signposting' to relevant support services where available
- advance care planning, including decisions about "ceilings" of care with coordination of care in and out of hours and across different care providers
- impeccable symptom control with regular inbuilt review of symptoms and their impact
- regular, open, honest, and sensitive communication with patients, carers, and professional staff about all aspects of their care
- referral for specialist palliative care when necessary

National Institute for Clinical Excellence (2004) Palliative care does not fit into a simple linear pathway of care; rather it oscillates depending on the lived experience of the patient and those close to them (Fig. 7.1.1). There are several challenges for those seeking to deliver good quality care in the last stages of any disease process. These include:

- prognostic uncertainty
- inadequate training around having difficult conversations
- inadequate training of professionals around palliative care principles
- lack of access to effective licensed medication for symptom control
- care systems which do not or cannot prioritize a palliative care approach

Palliative care assessment The timing of a palliative care assessment can be problematic. Modern understanding of the role of palliative care is reflected in the 'model c' outlined in Fig. 7.1.2, with the idea that palliative care steps in at key trigger points, such as worsening symptom burden,

and then withdraws, leaving the individual under the care of their current health and social care team until the next trigger occurs. Assessment involves impeccable attention to detail with targeted examinations and investigations. On the whole, interventions based on an understanding of the likely cause of a problem tend to work quickly and effectively. This is important as time can be short and in many instances there might only be 'one chance to get it right'. Given the scope of palliative care, a distinctive approach to clinical evaluation is required. Although a comprehensive palliative assessment includes all the standard elements of a medical history and relevant aspects of the physical examination, it also extends to exploring psychological, spiritual, and social domains.

Box 7.1.1 What is palliative care?—a case study

P was a 72-year-old man with 11-year history of chronic obstructive pulmonary disease related to smoking and his previous employment as a fireman. In the last six months he had become increasingly limited by breathlessness, making him chair-bound despite continuous long-term oxygen therapy via a concentrator. He felt no benefit from nebulized bronchodilators or his other inhaler, but continued to use them as prescribed. Despite multiple courses of oral antibiotics combined with bursts of oral steroids, he had a persistent productive cough with purulent sputum. He was referred to the palliative care team for management of his breathlessness and low mood after his third admission to hospital in four months. When referred he was breathless at rest, but able to talk in short sentences. He was just able to transfer from bed to chair with the help of his wife. He had pain in his chest from his persistent coughing as well as in his lower back from a long-standing injury sustained at work. He and his wife were exhausted by his poor sleep pattern. His wife was very concerned about his poor oral intake and low mood, feeling that P had started to 'give up'. At his first palliative care consultation, when invited to talk about his condition and what he understood was happening, P talked openly about the fact that his condition was deteriorating and he was not going to get better. He had spent a considerable amount of time mulling over his situation and said that he wanted to have as much time as he could with his family, particularly his grandchildren, but wanted to feel less breathless. He felt trapped in the house and guilty that he was being a burden to his wife because he was so dependent on her. He did not want to go to hospital unless absolutely necessary and was clear he did not want noninvasive ventilation, having had a bad experience with this in the past. P was taught relaxation techniques and breathing exercises and started on low-dose morphine to ease his subjective sensation of breathlessness. He attended a local hospice one day a week in an attempt to build up his confidence and emotional resilience. Within six weeks his subjective feeling of breathlessness had improved and he was able to walk short distances with a walking frame. He started to sleep better and eat a little more. His mood lifted as he was able to get out of the house for short trips using a wheelchair. Two months later his breathlessness had worsened, with pain in his back and legs and persistent nausea. Despite evidence of acute on chronic chest infection, after discussion with his wife and GP, he decided against hospital admission. P felt he was approaching the end of his life and did not want to pursue any potential life-prolonging interventions, including intravenous medication. After a further review both P and his wife decided they would prefer an admission to the local hospice for symptom control and possibly care in the last stage of his life. In the hospice he was found to be hypoxic. His oxygen was cautiously increased. He required a continuous subcutaneous infusion of painkillers and antiemetics to control his pain and persistent nausea. He died 10 days after admission with his wife and son by his bedside, having spent quality time with family and friends. With the support of staff in the hospice he had planned his own funeral and left letters for each of his grandchildren.

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Health/Social care view Individual view Oscillation Diagnosis Ceilings of treatment Advance care planning Care coordination Symptom control Managing reversible causes of deterioration Making sense of experience Coping with multiple losses Navigating care systems Managing impact on activities of daily living Managing emotions Coping with deterioration Fig. 7.1.1 Model of the dynamic nature of palliative care for individual patients. (a) The traditional model of late involvement of palliative services Condition-specific treatment Diagnosis Palliative care Death Condition-specific treatment Diagnosis Palliative care Death Condition-specific treatment Diagnosis Palliative care Trigger points Trigger points Source: NCPC, NEoLCP.96 Death (b) The model of early and increasing involvement of palliative services (c) The model of dynamic involvement of palliative services based on trigger points Fig. 7.1.2 Differing models of involvement of palliative care. Adapted with permission from National Council for Palliative Care.

626 Section 7 Pain and palliative care Being aware of the spiritual aspect of care is important for all medical staff, not just designated spiritual care providers such as chaplains. It is an aspect of care that can profoundly influence the outcome of difficult conversations. Spiritual assessment explores what gives an individual a sense of meaning and what helps them make sense of their world. For some this will include aspects of formal organized religion, but for most it will include themes such as family, nature, or the arts. For P, his family, in particular his grandchildren, were a core part of what gave his life meaning. Ensuring that he was able to leave a legacy for them in terms of individual letters was as important to him as ensuring his back pain was adequately managed. Who is involved in providing palliative care? All medical specialties will be involved in the care of individuals with progressive life-limiting illnesses. This requires an understanding of, and ability to deliver, a palliative care approach, which is important for all healthcare professionals regardless of their specialism. At its most effective, palliative care combines the contribution of informal care networks, including family, friends, and members of a local community with a well trained professional workforce, delivering care wherever the patient is and in a way they choose, as demonstrated by the case study at the beginning of this chapter. Providing good-quality palliative care is a challenge for resource-rich and resource-poor healthcare systems alike. The flexible and individualized approach palliative care requires can be hard to coordinate, requiring as it does excellent cross-boundary working between multiple agencies in a locality and systems that enable effective and timely transfer of care. Specialist palliative care is a specific approach to care provided by multidisciplinary teams who have undergone additional training on symptom control and other forms of psychosocial and spiritual support. Such teams often work with a patient's current care teams to support them to deliver the care needed when needs are complex and complicated, rather than taking over an individual's care. Specialist palliative care provision varies widely and might not be available in all care settings. Where there is a specialist team it might include consultants in palliative medicine, clinical nurse specialists, physical therapists, social workers, chaplains, and experts in psychological care. Specialist palliative care services might include inpatient units (hospices); hospital-based services including hospital support and outpatients; home care services; day care services; and bereavement support. Challenges to providing effective palliative care Prognostic uncertainty Most doctors overestimate the survival of terminally ill patients with a failure to recognize condition-specific triggers which signal when a palliative care approach would be appropriate. This, along with a lack of good clinical evidence, can lead to prognostic uncertainty making it hard to engage in the 'difficult' conversations that might be required. Some clinicians avoid the issue of end-of-life care altogether, using phrases such as, 'we

have to wait and see' or 'no one can tell' if asked about prognosis. Others might deal with the lack of certainty by carrying out more and more tests in the hope of being able to better predict the future. Both approaches strongly influence how a patient and those important to them understand what is happening, and how they engage in honest and open conversations about their care. Both can cause inordinate distress and misunderstanding. Adopting a palliative care approach does not preclude more active management where appropriate, using the concept of planning for the worst while hoping for the best. Clinical decisions might be finely balanced and need to consider the potential burden as well as benefit of any intervention offered. Doctors need to balance their clinical knowledge of the natural course of a disease process with the need to look for and manage reversible causes of a change in condition. Managing diagnostic uncertainty remains a significant challenge. Several prognostic measures have been proposed to enable more accurate determination of prognosis, but none has been established to be any more accurate than the 'surprise question', which simply asks, 'would you be surprised if this individual died in the next twelve months?' If you would not be surprised, then it is likely the individual is in the last year of their life. Equally important is the view of the patient and those important to them around their prognosis. As in our case study, P recognized he was not getting better and had already thought about what choices he wanted to make. This is not unusual, but such thoughts might not be voiced until the individual is invited to share them in a way that makes them feel confident that they will be heard and respected. Enabling a patient to make complex judgements about the potential benefit(s) of a course of action is at the heart of supporting them to make informed choices about their care. However, an individual's view of the balance of benefits and burdens will need to be regularly reviewed as the situation changes. Having difficult conversations

Excellent communication is essential in a palliative care approach, dealing as it does with difficult and emotionally charged issues such as not offering treatment, withdrawing established treatments, establishing ceilings of care including the appropriateness of attempting cardiopulmonary resuscitation, and the likelihood of dying soon. Among the recognized barriers to enabling effective communication in a palliative care setting are:

- Emphasis on diagnosis and treatment of physical dysfunction at the expense of psychological, social, and emotional aspects of the experience of the patient and those close to them.
- Professionals' assumptions about what is most distressing to patients.
- Giving advice and reassurance before the patient has had an opportunity to express their main concerns.
- Dismissing or minimizing the impact of distress.
- Avoiding any acknowledgement or exploration of feelings.

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Communication within palliative care aims to elicit and value the patient's story as much as give information or offer solutions. At its best, this patient-centred approach to care leads to negotiation and shared decision-making with patients based on mutual trust. This enables patients to:

- Discuss and understand their diagnosis and its implications.
- Make informed decisions and express preferences about goals of care and preferred place of care and death.
- Address 'unfinished business' including practical and legal issues and to receive appropriate psychological and spiritual support.
- Access information on eligibility for additional financial support (where available).
- Increase the likelihood of receiving appropriate end-of-life care in the place of their choice.

Capacity to make decisions

Patients with progressive life-limiting illnesses have to make complex and profound decisions about their care. To have the capacity to be able to make a decision, a person should be able to:

- Understand the decision to be made and the information provided about the decision including the consequences of making a decision.
- Retain the information given for long enough to make the decision. If information can only be

retained for short periods of time, it should not automatically be assumed that the person lacks capacity. Notebooks, for example, could be used to record information which may help a person to retain it.

- Be able to weigh up the information given and the pros and cons of making the decision.
- Communicate their decision to those around them. A person must be assumed to have capacity (to consent to or refuse treatments, or to make other care decisions) unless it is established that they lack capacity to make the decision in question. A person also has the right to make 'unwise decisions'. The responsibility for assessing and judging capacity lies with whatever professional is responsible for the decision-making process with the patient at the time. Some patients with an advanced illness such as heart failure, as well as more obvious conditions such as dementia, may have a degree of cognitive impairment which might affect their ability to understand and retain information. It remains essential that, where possible, they are involved in decision-making as much as they are able and as much as they want to be, while acting in their best interests. In these circumstances decisions must be based only on the patient's best interests, not those of their family. The ability to make decisions can vary over time and with the complexity of the decision to be made. In many instances, decisions might need to be made over several meetings to allow for patients' fatigue and frailty, as well as the emotional context. Engaging in complex conversations about future care when a patient is relatively well might be of benefit for patients and is part of the concept of advance care planning. In some countries patients can record, in advance of loss of capacity, their wishes, feelings, beliefs, and values to assist others to make best interests judgements if they later lose capacity (sometimes known as advance care plan or preferred priorities of care document). Such documents need to be regularly reviewed and communicated to all those involved in the patient's care across all care settings both in and out of hours, being updated as and when needed. Advance care plans commonly cover issues such as ceilings of care or treatment goals that are acceptable to the patient, as in our case study, preferred location of care, and the individuals they wish to be involved. In most cases, advance care plans are a statement of preferences and are not legally binding, but if not followed an individual doctor must be able to justify why they chose not to follow the preferences expressed in such a plan. In addition it might be possible to appoint an advocate to speak on behalf of an individual if and when they lose capacity. Anticipatory care can also involve prescribing symptom control medication 'just in case' so they are available and authorized to be administered when needed, avoiding undue delay in response to developing symptoms such as pain, nausea and vomiting, and terminal restlessness. It is essential that if this form of care takes place, clear guidance and procedures are in place to ensure the drugs prescribed 'just in case' are prescribed at the correct dose, and are used effectively and safely, only when required. Beyond marketing authorization (previously called a product licence) Many of the indications and routes of administration for drugs routinely used in palliative care are used outside the marketing authorization (MA) issued by the Medicines and Healthcare Products Regulatory Agency (MHRA) in the United Kingdom. This is usually because the original licence was for a different indication or for a different route of administration. For example, few medications are licensed for subcutaneous use but there is extensive experience of this route in palliative care. It is important to be aware that the responsibility for the consequences of prescribing a medicine beyond or without marketing authorization lies with the prescriber who must be fully informed, and
- balances both the potential good and the potential harm of using a medication beyond authorization;
- provides sufficient information to patients about the expected benefits and potential risks of using a medicine beyond or without MA;
- ensures the patient is aware that the Product Information Leaflet (PIL) prepared by the manufacturer will only contain information about licensed indications. Ethics and palliative

medicine There is a variety of ethical issues associated with palliative and end-of-life care, which often attract considerable public and media attention and can be a source of considerable complexity for individual practitioners. A detailed examination of these is beyond the scope of this chapter. The four bioethical tenets of respect for autonomy, beneficence, nonmaleficence, and justice might not adequately address an

628 Section 7 Pain and palliative care individual's personal preferences. This can lead to potential areas of conflict including 'the right to die' or the pursuit of 'treatment at any cost'. Making ethical judgements is further compounded by the paucity of evidence around end-of-life care. When there are dilemmas, seeking a breadth of opinion from across the multidisciplinary caring team, additional specialist advice as well as the views of the individual and their family before a treatment decision is made is essential. Conclusion Palliative care exemplifies all the principles that underpin good medical care, based as it is on the centrality of the patient and those important to them, attention to detail, relief of suffering in all its guises and excellent communication skills. It is everybody's business because we are all on the same journey and we all matter because of who we are not what we do.

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