
Care of the Dying Patient: A Guide for Nurses

1

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INTRODUCTION

Fifty-four per cent of deaths in England and Wales occur in acute hospital beds, 22% of people die at home and the remainder in other institutions, such as psychiatric hospitals (Office of National Statistics, 1999). Nearly 70% of deaths in the UK will be related to cancer, heart/circulatory disease and respiratory disease (Office of National Statistics, 2004). These figures imply that a significant proportion of patients will be receiving some form of care in the period prior to and at death, which necessitates health-care practitioners having the knowledge and skills to care for the dying patient. The pathway towards death may be a process of graduated illness involving many care services or completely unexpected, such as catastrophic trauma/cardiac arrest. The care needs of patients and their relatives, regardless of environment or cause or pathway, needs to be individualised and multifaceted to allow patients to approach death and to die free of symptoms and 'in peace' and to facilitate the support of bereft relatives.

The aim of this chapter is to provide an overview of the care of the dying patient.

LEARNING OUTCOMES

At the end of this chapter, the reader will be able to:

- Clearly define death and dying.
- Demonstrate an appreciation of the need for a multidisciplinary approach to care of the dying patient.
- Define and expand on nursing responsibilities and priorities in caring for the dying patient.
- Demonstrate an understanding of the Liverpool Care Pathway (LCP) for the dying patient and its implications for practice.

- ❑ Explore psychological, spiritual, social and religious/cultural aspects of care of the dying patient.
- ❑ Discuss the significance of and the treatment of symptom control in the care of the dying patient.
- ❑ Explore issues surrounding organ and tissue donation.
- ❑ Explore issues surrounding withdrawal of medical treatment.
- ❑ Discuss the role of palliative care nurse specialists.
- ❑ Discuss the role of support organisations in the care of the dying patient.
- ❑ Discuss the role of the hospice in the care of the dying patient.

DEFINING DEATH AND DYING

The current position in law is that there is no statutory definition of death in the UK (Department of Health (DH), 1998) owing to the fact that the definition of death is complex and subject to many influences.

One of the first documented definitions of death occurred as early as 1768 in the first edition of the *Encyclopaedia Britannica* (1973): 'Death is generally considered as the separation of the soul and body; in which sense it stands opposed to life, which consists in the union thereof'. Despite the phenomenal advances in science and technology since the 18th century, the earlier definition is the most approximate to how most lay individuals now conceptualise death.

Professional conceptualisation has been complicated. In early medicine, death was defined as the absence of respiratory sounds and an absence of heart sounds combined with unresponsiveness. However, these diagnostic criteria were easily challenged, firstly by certain recoverable conditions such as severe hypothermia/drowning and syncope mimicking death, and secondly by the development of cardiopulmonary resuscitation techniques. Descriptions of an individual 'returning to life' through 'resuscitation' were told in biblical times, and late 18th century scientific inquiry led to official reports of individuals being pronounced dead and being 'brought back to life'. Finally, moving into the 20th century, the development of artificial ventilators and cardiopulmonary bypass systems, and the use of pacemakers and organ transplantation became more commonplace; these devel-

opments confounded the definition of death further as patients could be kept 'alive' for periods of time.

The above-mentioned events led to the conceptualisation of death as a process rather than an assumption that the transformation from life to death was an instant one. In 1968, the Ad Hoc Committee of the Harvard Medical School (1968) defined brain death: 'A person is brain dead when he or she has suffered irreversible cessation of the functions of the entire brain, including the brain stem'. The report also outlined diagnostic criteria and the exclusion of preconditions for diagnosing brain death.

Determining death using neurological criteria, generally referred to as 'brain death', has been accepted for decades in most developed countries (Whetstine, 2007). However, the concept of equating brain death with 'death' has now been challenged, as brain dead individuals are at odds with our traditional intuition about death (Whetstine, 2007) and because of the physiological differences that exist between brain stem death and whole brain death.

The Department of Health (DH, 1998) recommended that the definition of death should be regarded as 'irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe'. The irreversible cessation of brain stem function produces this clinical state and therefore brain stem death equates with the death of the individual.

It is not inconceivable that advances in medical technology and knowledge may challenge this definition further in years to come.

Concept of a good death

Allowing a patient a 'good death' requires multidisciplinary, skilled and collaborative evidence-based care ranging from the simplest needs, such as positioning and communication, to advanced medical therapies.

The concept of a 'good death' is fluid and highly individual (Kehl, 2006). Bradbury (1999) suggests that a 'good death' can be described as a good 'sacred death', where one may die at peace 'spiritually', a good 'medicalised death', where there is freedom from pain and symptoms, or a good 'natural death', which is best conceptualised as passing away/passing on, or dying within sleep. However, these descriptions are not all-encompassing and

may be subject to sociocultural variance and other influences. Kehl (2006), following a review of medical, nursing and patient perspectives as well as literature in sociology, suggests that individuals consider the following attributes as characteristic of a good death:

- Being in control.
- Being comfortable.
- A sense of closure.
- Trust in care providers.
- Recognition of impending death.
- Personal beliefs and values honoured.

A patient's perceptions of what he/she considers to be a good death must be explored to allow holistic care planning to meet his/her needs for a good death.

Principles of palliative care

The main priorities of nursing care in nursing the dying patient are to assist the individual to meet his or her personal needs leading up to death and to allow that individual a 'good' and 'peaceful' death.

The term 'palliative care', first proposed in 1974, encompasses this philosophy, moving the focus of care away from attempting to cure or preventing dying to improving the quality of life, through the prevention and relief of suffering in the time leading up to death. The World Health Organisation (www.who.int/en) suggests that 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.

- Enhances 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.

A framework for meeting the fundamental nursing needs of the dying patient is suggested in Table 1.1.

Table 1.1 Key components of nursing care in nursing the dying patient

Core component/goal	Elements of care
Effective pain control	<ul style="list-style-type: none"> • Pain control is assessed continually • Administration of appropriate analgesia/analgesic delivery methods • Consideration of other methods of promoting comfort (heat pads/positioning, etc.) • Specialist advice is sought if necessary (e.g. a chronic pain service)
Patient is free from agitation/distress	<ul style="list-style-type: none"> • Continual assessment for agitation/distress • Providing an environment that allows the patient/family to communicate their fears/anxieties • Providing an environment that is conducive to privacy • Administration of appropriate anxiolytics as prescribed • Ensure that inappropriate interventions are discontinued
Patient is free from nausea/vomiting	<ul style="list-style-type: none"> • Continual assessment for nausea and vomiting • Administration of anti-emetic medication as appropriate/prescribed
Optimum management of any potential side effects of medication or management	<ul style="list-style-type: none"> • Appropriate nursing management of conditions such as dyspnoea, oedema and increased respiratory secretions • All nursing care to be delivered to reduce the risks of infection transmission
Optimum management of elimination/bowels	<ul style="list-style-type: none"> • Monitoring bowel movements • Enabling multidisciplinary management to avoid constipation/diarrhoea • Administration of appropriate medication as prescribed

Table 1.1 *Continued*

Core component/goal	Elements of care
Mobility/hygiene	<ul style="list-style-type: none"> • To avoid complications of immobility • Ongoing assessment of skin integrity • To prevent pressure ulcer formation • Utilisation of appropriate pressure relieving aids • Provision of hygiene needs, to include oral/eye care
Religious/spiritual needs	<ul style="list-style-type: none"> • Providing access to religious/spiritual support as required • The consideration of cultural needs in all aspects of care
Psychological support for the patient and his/her family	<ul style="list-style-type: none"> • The patient and his/her family are informed (as appropriate) of all procedures and care and the rationale for these • Assessment of the understanding of the patient's closest relatives, obtaining consent for passing on information • Ensure that patient and family are aware of treatment/care goals

MULTIDISCIPLINARY AND MULTI-AGENCY APPROACH IN CARING FOR THE DYING PATIENT

Multidisciplinary teams (MDT) are groups of professionals from similar and/or diverse disciplines who come together to provide comprehensive assessment, care and treatment for the patient. The team work collaboratively and cohesively to meet agreed objectives and outcomes. It would be difficult to argue that this approach is inferior to any other. However, it has been argued by Walton (2005) that health care in general is not routinely delivered by such teams and that the concept is more a theoretical ideal than a reality. At its best, the approach could meet the needs of patients and their relatives/significant others whilst developing staff and creating a process of ongoing improvement in the quality of care and clinical governance. However, if the MDT does not function effectively, care can become fragmented and outcomes could be detrimental to all concerned.

The size and composition of the MDT vary; complex cases such as those in palliative care may involve primary and secondary

care teams, different agencies, including charitable organisations, and specialist palliative care services.

It is beyond the scope of this text to explore team structure and team dynamics; however, the basic fundamental component to any team approach to working is good multi-layered communication. Every MDT or service should implement processes to ensure effective inter-professional communication within teams, and between them and other service providers with whom the patient has contact (National Institute for Clinical Excellence (NICE), 2004).

Bliss *et al.* (2000) identified the key components to successful inter-professional working in palliative care as:

- Team members sharing a common medical and healthcare language.
- Individuals working within the team should be prepared to work together and not feel under threat from other professional groups.
- Individual team members placing value on the different contributions that can be made by each individual.
- A sharing of professional values and cultures.

Whilst these values are suggested for palliative care teams, they are essential for any team in order to meet the needs of any patient, not least in death.

The team should not be 'hospital-based', or 'community-based', but patient need-based. All MDTs and services should have mechanisms in place to gather the views of patients and carers on a regular basis (NICE, 2004), with every role and discipline being seen as an integral component. An overall team co-ordinator should be identified, although this individual must not be viewed as being 'the boss'; it should be an individual who communicates regularly with the patient and all members of the team. Mechanisms should be developed to promote continuity of care; this might include the nomination of a person to take on the role of 'key worker' for an individual patient (NICE, 2004).

The development of an MDT approach should be an ongoing process and should consist of collaborative meetings and training/education.

FRAMEWORKS FOR CARE OF THE DYING PATIENT

One of the key recommendations in the NICE document *Improving Supportive and Palliative Care for Adults with Cancer* (NICE, 2004) is that in all locations, the particular needs of patients who are dying from cancer should be identified and addressed. The Department of Health (DH, 2008) suggests the following three coordination processes for care of the dying patient.

Gold Standards Framework

The Gold Standards Framework (www.goldstandardsframework.nhs.uk) is designed to care for people with advanced, progressive, incurable illness, mainly in the primary care setting. It enables general practitioners (GPs) to identify patients for inclusion on the palliative care register. This approach helps primary care teams to work together in optimising continuity of care, teamwork, advance care planning, symptom control and patient, carer and staff support (DH, 2008).

Preferred Priorities for Care

The Preferred Priorities for Care (PPC) (www.endoflifecareforadults.nhs.uk) is a patient-held ambulatory document. It clearly outlines individuals' thoughts about their care and choices they would like to make. Preferred Priorities for Care aims to ensure seamless continuity of care, promote patient empowerment and provides the opportunity to discuss difficult issues that may not otherwise be addressed, to the detriment of patient care (DH, 2008).

Liverpool Care Pathway

The Liverpool Care Pathway (LCP) for the dying patient has been developed in the UK to transfer the hospice model of care of the dying into other care settings. It is a multiprofessional document that provides an evidence-based framework for care in the last days and hours of life, and is applicable to all care settings. The LCP is based on the principle of the integrated care pathway, a care method that aims to facilitate distinct care through integrated multidisciplinary cooperation (Veerbeek *et al.*, 2006). Integrated care pathways are structured care plans which detail

essential steps in the care of patients with a specific clinical problem (Campbell *et al.*, 1998).

The pathway comprises three stages: initial assessment, ongoing assessment and after-death care. Each of these stages has specific evidence-based goals, which may or may not be achieved. If the goal is not achieved, it will be recorded as a variance from the normal plan of care. This, however, does not imply a failure in care; it may reflect care individualisation within the framework.

The LCP is designed for patients with life-limiting illness where the primary goal in care is provision of comfort. Multidisciplinary agreement should be made that if the patient is dying, all possible reversible causes for the current condition have been considered, and the patient may be two or more of the following:

- Bed-bound.
- Semi-conscious.
- Unable to take oral fluids.
- Unable to take tablets.

The key stages and patient goals of the LCP are demonstrated in Table 1.2.

Research evaluating the effectiveness of the LCP in practice is still relatively young, although promising. The pathway can facilitate 'simple' audit, for example which areas score highly in recorded variance, which can identify areas for future work, etc. Similar care pathways for the dying patient exist, such as the Supportive Care Pathway developed by the Pan Birmingham Palliative Care Network; again evaluation is in its infancy, although promising (Main *et al.*, 2006).

One of the key benefits of frameworks such as the LCP is that they are adaptable, in essence, to the clinical scenario, not least to cancer patients and those with long-term illness. The underlying principles of the programme should not be exclusive to cancer patients and should be considered for any patient meeting the above-mentioned criteria with life-limiting illness; this may include any end-stage organ system failure. Work is currently underway to explore the adaptability of the LCP to paediatrics, critical care, renal care and respiratory care scenarios.

Table 1.2 The Liverpool Care Pathway – Key stages and patient goals. Reproduced with kind permission of the Marie Curie Palliative Care Institute Liverpool (MCPCL)

Stage	Focus/stage specifics	Assessment/patient goals
Initial assessment	Medical assessment, including the cessation of inappropriate therapy and medication, forward planning for treatment symptoms and an assessment of appropriate nursing care needs	<ul style="list-style-type: none"> • Physical assessment • Assessment of comfort • Psychological assessment • Assessment of psychological needs/insight into condition • Assessment of religious/spiritual needs • Assessment of communication needs
Ongoing assessment	Four-hourly nursing assessment of symptom control	<ul style="list-style-type: none"> • Pain • Agitation • Respiratory tract secretions • Nausea and emesis • Other symptoms such as dyspnoea • Oral hygiene • Elimination needs • Safe delivery of medication • Mobility/pressure area care • Psychological support • Religious/spiritual support • Needs of family/significant other
Care after death	Discussion with family Correct documentation	<ul style="list-style-type: none"> • Last offices • Property/valuables • Family information • Bereavement booklet • Informing GP/appropriate organisations

SYMPTOM CONTROL AND THE MANAGEMENT OF UNWANTED SIDE EFFECTS IN THE CARE OF THE DYING PATIENT

Disease processes and the management of a disease can produce a variety of symptoms and potential side effects. These symptoms may be physiological, psychological, social or spiritual in origin

and may be influenced by many sociocultural variables. The effects of symptoms may be manifested in the dying patient who, by definition, may have little physiological reserve; this may result in severe distress. Many symptoms may be a result of medication and possible interactions between different medications. Multidisciplinary review of the patient's medication should occur throughout the dying phase to ensure that only drugs that are considered essential (those aimed at treating symptoms) should be administered. This may require the discontinuation of drugs previously considered essential, such as antihypertensives, etc.

When caring for the dying patient, the management of symptoms must be a high priority in order to improve the patient's and the family's experience of end-of-life care. Many cancer patient surveys demonstrate that symptom control has a high priority from both patients and carers (DH, 2000), and that the fear of inadequate control leads to severe distress (Steinhauser *et al.*, 2000).

It has been suggested that symptom assessment and control may be sub-optimal (NHS End of Life Care Programme, 2006) and differences may exist between primary and secondary care (Thomas, 2003), which may necessitate unwanted hospital admission. It has also been suggested that patients with organ system disease, such as chronic heart failure, miss out on the benefits provided to many cancer patients, particularly in relation to symptom control.

Cancer network-wide protocols and guidelines should be developed and implemented for symptom control (NICE, 2004), and these should be adaptable to other end-of-life disease situations. Certain tools have been devised for assessment of symptoms as part of the Gold Standards Framework and these are available from the website of the organisation (www.goldstandardsframework.nhs.uk). Many dying patients, particularly those in hospital, are not managed by the palliative care team and, as a result of this, the management of symptoms may not be optimal. An integrated care pathway provides one solution to this problem by giving the healthcare team a way to improve patients' access to high-quality symptom assessment and treatment in terminal care in general (Glare, 2003).

The diversity of symptoms that a patient may experience is particularly wide and specialist multidisciplinary advice should be sought from a variety of sources.

Symptoms that cause specific distress to patients include:

- Inadequate pain control.
- Agitation and distress.
- Increased respiratory tract secretions.
- Nausea and vomiting.
- Loss of appetite.
- Insomnia.
- Dyspnoea.
- Constipation.
- Urinary problems.

The first four in this list are the most common symptoms (Turner *et al.*, 1996) and these require specific mention.

Inadequate pain control

Individualised pain management in the dying patient should consist of: (a) identifying and treating the cause of pain if at all possible; (b) treating any factors that could be contributing toward pain, such as agitation and distress; (c) the use of appropriate analgesic agents, delivered via an appropriate route; and (d) the consideration of non-pharmacological pain relief.

The effectiveness of therapy should be evaluated at regular intervals, with the goal being pain control rather than pain relief.

Agitation and distress

Agitation, distress and delirium can compound other symptoms, particularly pain. Their presence can significantly reduce quality of life in the days/hours leading up to death. They may also cause distress to relatives and loved ones. Identifying and treating the cause of agitation is frequently difficult, particularly in the delirious patient or those with fluctuating levels of consciousness. Emotional distress is a predominant cause for distress and can be reduced by good communication and psychological support. Distress as a result of constipation/urinary retention or dyspnoea should be identified and treated accordingly. Metabolic

disturbance, electrolyte/hydration imbalance and drug toxicity are also causes for altered mental state, although treatment may be more difficult. Glare (2003) suggests that correction of hypo/hyperglycaemia is the only metabolic derangement that is worth correcting in the last 48–72 h of life. Pharmacological treatment for unresolved agitation and distress is common and this may consist of sedative and antipsychotic drugs.

Increased respiratory tract secretions

The phenomenon of noisy breathing in the hours before death is commonly referred to as the ‘death rattle’ and is a result of the movement of pooled respiratory secretions during respiration (Hugel *et al.*, 2006).

This may contribute to the development of terminal restlessness (Dickman, 2003). Treatment may consist of simple manoeuvres such as position change or suction; however, this may cause increased distress to the patient. The early introduction of antimuscarinic drugs may play a role in reducing secretions (Wildiers & Menten, 2002).

Nausea and vomiting

Many ill patients experience nausea, frequently without vomiting. It can occur in up to 62% of terminally ill patients with cancer (Rosseau, 2002). It may be exacerbated by gastro-intestinal problems, metabolic derangement or may be an adverse result of medication, particularly opiates. Although the causes are usually multifactorial, treatment should be aimed at any identified cause. Appropriate anti-emetic therapy should be initiated according to local drug guidelines.

The LCP recommends anticipatory medication prescribing for the top five symptoms that may be expected in the last hours/days of life. This enables a patient to receive medication appropriately without having to leave a patient in pain, for example whilst a doctor is contacted. Patient care and the management of symptoms may also improve with the advent of non-medical prescribing. (DH, 2006). Likewise, collaborative teamwork will be required to ensure that resources such as drugs, syringes and syringe drivers are available at the point of care.

PSYCHOLOGICAL, SOCIAL AND SPIRITUAL CARE OF THE DYING PATIENT

Psychological distress is common among people affected by cancer and is an understandable response to a traumatic and threatening experience (NICE, 2004). This distress often causes suffering in the patient nearing the end of life (Block, 2000). At the time of diagnosis of dying, approximately 50% of all patients experience anxiety and depression severe enough to affect their quality of life. In the subsequent 12 months, 1 in 10 people develop psychological symptoms severe enough to warrant specialist intervention (NICE, 2004). Although some literature discusses the psychological issues facing older patients and terminally ill patients with cancer, less is known about patients with end-stage pulmonary, cardiac, renal and neurologic disease (Block, 2000). The experiences of facing the end of life, regardless of disease process, are inevitably similar.

A large volume of work looking at patients' attitudes and responses towards death and dying or dealing with catastrophic news is influenced by the work of Elisabeth Kübler-Ross (1969), who suggested that patients journey, although not sequentially, within five stages of grief (as demonstrated in Box 1.1). This model has been criticised, not least because it considers all

Box 1.1 The five stages of grief according to Dr Elisabeth Kübler-Ross

- Denial: 'It can't be happening.' The initial stage of shock and numbness. A conscious or unconscious refusal to accept facts.
- Anger: 'Why me?' Anger may be internalised or externalised against the clinician, family or the individual's God.
- Bargaining: 'Just let me live to see my grandchild born.'
- Depression: The initial stages of acceptance.
- Acceptance: A stage where there may be some emotional detachment and objectivity.

These stages are not sequential and movement through the stages may be highly individualised and fluid

patients as experiencing similar pathways, and has limitations in its interpretation and development (Germain, 1980). However, the model does encompass a wide range of emotions that the dying patient, or bereft relatives, may experience. The psychological response to approaching the end of life will be influenced by a multitude of factors, including religion, faith, age, culture, social networks, finances and personal beliefs. To some, death may be welcomed, to others it may be feared.

Many patients utilise their family and social networks to express their views and fears. Some patients (the majority), however, are likely to benefit from additional professional intervention because of the level and nature of their distress (NICE, 2004). Providing psychological, social and spiritual care to the dying patient is a complex aspect of care provision, not least because these needs will be highly individualised. Care may also be influenced by the healthcare practitioner's knowledge, skills and attitudes regarding end-of-life care. Often, healthcare providers and families of dying patients are reluctant to accept that a dying individual's priority may be spiritual guidance, rather than technologically advanced medical care (Proulx & Jacelon, 2004). Trovo de Araujo & da Silva (2004) suggest that there are many different individual approaches in the endeavour to communicate with terminally ill patients, including avoidance patterns, which may be a result of personal difficulties in coping with the reality of human suffering and death.

The underlying principle in providing psychological, social and spiritual care to the dying patient is good communication, which leads to dynamic assessment and planning of end-of-life care.

Psychological care

Providing psychological support to help patients to face death should begin at the point of diagnosis; to a large proportion of patients this may be a time of severe shock and disbelief that 'this is happening to them'. They may have many questions that need answering honestly. Assessing psychological needs should begin with assessing patients' insights into their condition. Many patients who have been informed that 'they are going to die as a result of the illness' may have little knowledge of this fact.

Information provided may have been delivered badly, misinterpreted or misheard from initial discussion. Assessing insight informs the practitioner what information/services may be required. Issues related to dying and death should be explored appropriately and sensitively. Callanan & Kelley (1992) insist on the value of honesty in the nurse–patient relationship when describing the physiological process the patient experiences.

NICE (2004) recommend a four-level model of psychological assessment and intervention (Table 1.3). In this model, the patient progresses through four stages of assessment/care, starting with healthcare professionals at all levels, progressing to mental health specialists. The model may have many advantages, not least in providing access to highly trained practitioners with considera-

Table 1.3 The four-level model of psychological assessment and intervention

Level	Group	Assessment	Intervention
1	All health and social care professionals	Recognising psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health- and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem-solving
3	Trained and accredited professionals	Assessing psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety and solution-focused therapy, delivered according to a specific theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy and cognitive behavioural therapy

ble experience in psychological assessment and care. It also allows for patient needs to be met by a variety of sources. However, unless good communication exists between the professional groups, the model is futile, as care will fragment.

Price *et al.* (2006) suggest that delivery of the NICE guidelines, regarding the provision of psychological support, may be compromised by limited availability of specialist services and that this area needs further research.

Social care

As individuals approach the end of life, they may draw on the support of their family, friends and loved ones or 'significant others'. Healthcare practitioners have a responsibility to provide support for these individuals and be aware that family members will also be progressing through stages of grief and impending loss and will have their own psychological needs. The family's insight into the patient's condition should be assessed, and issues relating to dying and death explored appropriately and sensitively (Ellershaw & Ward, 2003). However, staff must be aware of breaching confidentiality and ensure that information is provided with a person's consent if he/she is able to provide it. Healthcare staff must ensure that ambiguous language is avoided when communicating with relatives. Relatives should be aware that the patient is going to die and that treatment and care is directed at allowing a good death. Questions should be encouraged and opportunities given for them to spend time with the patient. Relatives should be able to access support in the time leading up to death and following death. To provide a broader aspect of social care, communication should exist between the MDT and social care organisations, whose services impact on patient well-being both during the time leading up to and after death. This may include advice regarding financial arrangements and continuing care services.

Spiritual and religious care

Spirituality can be defined as, 'a search for existential meaning within a life experience, usually with reference to a power other than self, not necessarily called "God", which enables transcendence and hope' (Ellershaw & Wilkinson, 2003).

Religion can be defined as, 'belief in, worship and faith in a supernatural power which controls human destiny.'

Evidence suggests that religious and spiritual issues are significant for many patients and their carers in the last year of their life and that most patients' spiritual needs centre around their loss of role, self-identity and their fear of dying (Murray *et al.*, 2004). The needs of patients for spiritual support are, however, frequently unrecognised by health and social care professionals, who might feel uncomfortable broaching spiritual issues (NICE, 2004).

Providing spiritual care cannot be undertaken by only determining the patient's religion. A person's spirituality may or may not be religious in its foundation; a non-religious person may still have deep spirituality and spiritual needs (Speck *et al.*, 2004). To meet a patient's religious and spiritual needs, a comprehensive assessment is required, and this process needs to be continually reassessed throughout care as needs differ and change throughout the process leading up to death.

Healthcare staff need to be sensitive to, and have an awareness of, many cultural and religious backgrounds to better facilitate care. Staff also need to be able to value individuals' relationships with their chosen faith, beliefs and values. Healthcare staff have a responsibility to provide access to qualified, authorised and appointed spiritual care. They should also be aware of local community resources for spiritual care (NICE, 2004).

Formal religious traditions may have to be observed in the dying phase and may also influence care of the body after death (Ellershaw & Ward, 2003). Observing these traditions may also play an important role in the relatives' grieving process and acceptance of death.

Certain cultural and religious groups view death in different ways and employ certain practices with regard to death, dying and bereavement. A brief overview of some of these practices/views is presented in Table 1.4. However, these will be subject to various influences and should not be treated as definitive.

WITHDRAWAL OF MEDICAL TREATMENT

In any medical setting, the most important factors that must be considered in determining a treatment plan are the wishes and

Table 1.4 Some religious/cultural considerations when caring for the dying patient. Adapted from *Death with Dignity* (Green, 1993)

Religion	Common themes
Islamic (Muslim)	<ul style="list-style-type: none"> • Approaching death, close friends and family spend time in attendance to help the dying person to iterate his or her commitment to unity of God via prayer. This group may be large in comparison, with traditional views of 'close family and friends' • The dying patient may wish to lie with his or her face towards Mecca (the religious centre for Muslims) • Sick patients are not expected to fast during the month of Ramadan • Muslim relatives may request that the body is not touched by non-Muslim hands and therefore gloves should be worn during last offices • On death, the body is washed and wrapped in a shroud. Muslims gather and a prayer is performed for the dead • The body is buried (not cremated), with the head facing Mecca, as soon as possible • Charity, fasting, prayers and pilgrimage are often performed on behalf of the dead • Some confusion exists around organ donation as this interferes with burying the body as soon as possible • Post mortems are likewise not welcomed • If referring to the Coroner, identify religion as this may allow more prompt release of the body
Hinduism	<ul style="list-style-type: none"> • During end of life, devout Hindus may receive some comfort from readings from the Hindu holy texts • A Hindu priest may scatter holy water, tie a thread around the wrist or place a sacred leaf on the person • Hindu relatives may request that the body is not touched by non-Hindu hands and therefore gloves should be worn during last offices • Jewellery/threads should not be removed • After death, cremation is usual for adults, although children may be buried • Many Hindus prefer to die at home • Close relatives of the deceased may observe a 13-day mourning period. Close relatives may wish to spread the deceased person's ashes in the River Ganges. • Close male relatives of the deceased may shave their heads as a mark of respect. • Cremation should occur as soon as possible. • No objection is generally expressed towards organ donation/post mortem, although the latter is disliked

Table 1.4 *Continued*

Religion	Common themes
Judiasm	<ul style="list-style-type: none"> • A dying Jew may wish to hear psalms being sung or a special prayer (The Shema). They may also wish to hold the page of the Psalm or prayer. • At death, the child of the deceased may wish to close the eyes, this should be done as soon as possible after death. • Burial should occur within 24h although not during the Sabbath (nightfall on Friday until Saturday evening). Some more liberal Jews wish to be cremated. • If death occurs during the Sabbath, many orthodox Jews may resent moving the body until it is over. • If a Coroner's referral is necessary, he should be informed about the body • Following death, immediate family may stay and mourn at home for 7 days. • Generally, no objection is expressed towards organ donation although this may differ in orthodox Jews.
Sikhism	<ul style="list-style-type: none"> • During the end of life, some Sikhs may receive comfort from readings from Guru Granth Sahib (The Sikh Holy book) • After death, many Sikh families may wish to attend to last offices themselves. • During last offices, the hair should not remain covered (under no circumstances cut). • Sikhs are usually cremated and have a preference for this to take place as soon as possible after death. Small children and babies may be buried
Buddism	<ul style="list-style-type: none"> • No objection is generally expressed towards organ donation • The important consideration is the state of the mind prior to death, which ideally will be a time of peace. Drugs which sedate or cloud conscious level may be refused. • At the time of death, it is important to inform a Buddhist monk or a Minister as soon as possible. • Most Buddhists prefer cremation. • No objection is generally expressed towards organ donation/transplantation or post mortem.

autonomy of the patient (Kinoshita, 2007). Underlying this principle is the issue of informed consent. Information should be provided to the patient, including benefits/negative effects, probability of effectiveness and potential alternatives to a treatment in order for the patient to make a balanced decision regarding whether the treatment is wanted or not. The MDT has a

responsibility to ascertain that the patient is competent to make that decision, according to guidelines outlined in the Mental Capacity Act (Department for Constitutional Affairs, 2005). Patients may wish to change their minds about the treatment once it has begun and therefore should be provided with all the necessary information and their wishes adhered to.

Many patients are competent to express their views and issue directives regarding their medical care and treatment, particularly those in progressive disease processes. However, many patients die as a result of a catastrophic, short-term illness, necessitating 'artificial life support' therapy and are not able to make these decisions. Likewise, patients may become unconscious as result of treatment/disease and cannot make their own decisions. In this case, the Mental Capacity Act should be consulted. (The basic principles of the Mental Capacity Act are demonstrated in Box 1.2.)

Box 1.2 The Mental Capacity Act (2007)

The main changes as a result of the act are:

- There will be a single clear test for assessing whether a person lacks capacity to make a decision.
- The provision of ways in which individuals can influence what happens to them in the future, such as Lasting Power of Attorney (LPA), advance decisions, etc. An LPA will allow people over the age of 18 to formally appoint someone to look after their health, welfare and/or financial decisions.
- The clarification of what actions need to be taken when someone lacks capacity.
- Obligation to consult everyone involved in someone's care/interested in their welfare.

The central components of the act are:

- Every adult has the right to make their own decisions and be assumed to have capacity to do so unless proved otherwise.
- People must be supported as much as possible to make their own decisions before anyone concludes they cannot do so.

Continued

- People have the right to make what others might regard as unwise or eccentric decisions.
- Anything done for, or on behalf of, people who lack mental capacity must be done in their best interests.
- Anything done for, or on behalf of, people without capacity should be the least restrictive of their basic rights and freedoms.

With regard to acting in a patient's best interests, the decision-maker should:

- Not make assumptions about someone's best interests based merely on age, appearance or behaviour.
- Consider all the relevant circumstances relating to the decision in question.
- Consider if a person is likely to regain capacity – can the decision wait until then?
- Involve the person as fully as possible in the decision that is being made on his or her behalf.
- With regard to withdrawal of life-sustaining treatment, the decision-maker must not be motivated by a desire to bring about the person's death.

Patient decisions regarding refusal of treatment must be:

- Valid.
- Applicable to the treatment in question.
- In writing.
- Signed and witnessed.

A patient cannot:

- Make an advance decision to ask for medical treatment.
- Make an advance decision to ask for their life to be ended.

This also applies to the initiation of cardiopulmonary resuscitation in the event of cardiac arrest. Current medical emphasis on autonomy requires that patients be primary in authorising do-not-resuscitate orders (Elliot & Olver, 2007), yet this may not always be achievable.

Any medical treatment must follow the ethical principles of beneficence and non-maleficence (Eschun *et al.*, 1999). In many cases, it can be argued that the continuation of medical treatment

and intervention is not in the best interests of the patient. This is particularly relevant in patients approaching the end of life through disease and ill health, most notably organ system failure and cancer. Thus the most appropriate route of care may be the withdrawal of treatment.

Withdrawal of treatment is not uncommon in certain clinical settings, yet little work has been published exploring the issue that is, in the main, applicable to intensive care scenarios. There are numerous ethical and legal dilemmas associated with withdrawal of treatment, as was demonstrated in the Tony Bland case of the early 1990s where the question what constitutes medical treatment was raised (Howe, 2006). Withdrawal of treatment can vary from the discontinuation of antibiotics to the withdrawal of advanced renal/cardiovascular support. What should not be withdrawn is analgesia and treatment aimed at reducing distress and any symptoms.

The most important component of withdrawal of treatment is that it does not equate with withdrawal of care. Care to ensure the comfort of a dying patient is as important as the preceding attempts to achieve cure (Winter & Cohen, 1999).

The following criteria should be present when considering the withdrawal of treatment:

A situation where continued treatment would provide no overall benefit to the patient and may prolong unnecessary suffering.

or

A situation where there is irrefutable evidence that brain stem death has occurred.

The overall responsibility for withdrawal of treatment is with the patient's consultant. However, multidisciplinary discussion and agreement should be sought. In the UK, the patient's relatives do not have legal rights of decision-making (Winter & Cohen, 1999), but this should not exclude them from these discussions. It is imperative that relatives comprehend that they do not have to make a decision as this may be perceived as an overwhelming burden placed on them.

In accordance with the Mental Capacity Act, a Lasting Power of Attorney (LPA) has the right to make decisions regarding the initiation of life-saving treatment (such as cardiopulmonary

resuscitation) and the withdrawal of life-sustaining treatment, only if this is specified in the legal documentation. An LPA may wish to continue medical treatment despite discordance with what is perceived as in the patient's best interests. The final responsibility for deciding what is in a person's best interest lies with the member of healthcare staff responsible for the person's treatment (the consultant). If agreement cannot be reached through excellence in communication, an application may be made to the court of protection.

Difficulties may arise in the withdrawal of treatment if:

- (1) The patient requests discontinuation of therapy.
- (2) The patient's family requests continued futile therapy.
- (3) There is a lack of multidisciplinary agreement about withdrawal.

Appropriate communication with regard to the rationale of decision-making must be fully explained to relatives, with particular emphasis on the duty of care to the patient and the patient's best interests.

The MDT may often have differences of opinion with regard to withdrawal; again 'what is in the patient's best interest' should be the essential component of any discussions. Senior clinical experts should be involved in all discussions.

ORGAN DONATION

The role of organ and tissue transplantation in health care is well established and continues to develop as a result of advances in technology, surgical technique and immunosuppressant therapy. Currently, the demand for transplant organs, particularly kidneys, far exceeds the supply in the UK (Darr & Randhawa, 1999). The number of transplants performed in the UK has remained virtually static over the last 10 years; during this interval, the number of donors has decreased by approximately 20% (DH, 2004).

The supply of organs for donation usually comes from three sources:

- A 'heart beating' donor that is certified as brain stem dead on respiratory support.

- A living person who consents to organ donation.
- A non-heart beating donor.

The brain stem dead patient

Damage to the brain stem may occur as a result of intracranial or extracranial insult, the common causes being intracranial hypertension, trauma and cerebral anoxia. In many unconscious, unresponsive patients cardiopulmonary support is initiated and brain stem dysfunction realised after the event. In these patients, brain stem testing in line with the code of practice for the diagnosis of brain stem death (DH, 1998) is appropriate.

According to this code of practice, a patient may be certified as brain stem dead when:

- There is no doubt that the patient's condition is due to irremediable brain damage of known aetiology.
- The patient is deeply unconscious.
- There is no evidence that the state is due to depressant drugs.
- Primary hypothermia as the cause of unconsciousness has been excluded.
- Potentially reversible circulatory, metabolic and endocrine disturbances have been excluded as the cause of the continuation of unconsciousness.
- The patient is being maintained on the ventilator because spontaneous respiration has been inadequate or ceased altogether.
- All brain stem reflexes are absent.

When brain stem death has been established by the methods outlined in the code of practice, the patient is dead even though respiration and circulation can be artificially maintained (DH, 1998). At this stage, it becomes appropriate to consider whether any of the dead patient's organs can be made available for transplant prior to discontinuation of cardiopulmonary support (DH, 1998). If organ donation is not appropriate, cardiopulmonary support is discontinued at the completion of a second set of brain stem death tests. For legal purposes, the time of death is recorded as the completion of the first set of tests.

It is pertinent to emphasise that whilst cardiac and circulatory function may continue in the brain dead patient, the pathophysiological processes associated with brain stem death result in cessation of heart beat over a short period of time.

Obviously, consent for organ donation cannot be expressed by the patient. Consent may be assumed if a patient has expressed a wish to donate organs prior to illness; the generally accepted route of doing so is via the organ donor register or by carrying a donor card, although many individuals express wishes to their close family. In a case of a person who has signed the organ donor register, family members have no legal right to veto this person's wishes (Human Tissue Act, 2004), although this situation requires exceptionally skilled handling and communication from a healthcare team. If a patient has been certified as brain stem dead on the first set of tests, it is usual practice for the family to be approached by healthcare staff to explore what the patient's views were towards organ donation; again this process requires exceptional communication skills. Most transplant centres employ procurement transplant co-ordinators who have immense experience and skills in this field and they should be consulted at the earliest opportunity.

Brain stem death and the process of organ donation from a brain stem dead patient is particularly traumatic for relatives, as their perceptions of how their relative appears on the intensive care unit differs from their preconceived perceptions of a 'dead person'. Again, excellent communication and possible in-depth discussion regarding perceptions of death need to be ventured into.

Non-heart beating donation

Organ transplantation originated in taking organs from people who had recently died, but many of these transplants failed because organs had suffered damage as a result of ischaemia. Necessitated by the increasing demand for organs, organ retrieval shortly following the moment of cardiorespiratory death (non-heart beating organ donation) is now being revisited. The advantage of the system is that the patient is able to provide consent for organ donation or can make an advanced directive to this effect.

Although the re-visitation of this process is in its infancy, the process typically occurs in critical care units where active treatment has been withdrawn. When this occurs, a transplant coordinator is contacted and suitability for non-heart beating organ or tissue donation is assessed. Death is certified following loss of cardiorespiratory function. The body is cooled aggressively and taken to theatre for organ retrieval. In some cases, femoral arteries are cannulated prior to death, which reduces ischaemic time. The process is predominantly used for kidney donation.

However, there are many implications and concerns with non-heart beating donation. First and foremost is the concept of death as a process and the differences between cardiopulmonary death and neurological death. It could be questioned whether death has really occurred. This is complicated further by a situation known as the Lazarus effect, where some cardiac function returns some time after asystole and the withdrawal of resuscitative measures (Maleck *et al.*, 1998; Adhiyaman & Sundaram, 2007). It is accepted by the British Transplant Society that an interval of five minutes between the cessation of cardiopulmonary function and the declaration of death provides adequate assurance of the irreversible cessation of cardiopulmonary function (British Transplant Society, 2004).

Other considerations are practical and cost-based, with regard to place of care and withdrawal of treatment, intensive care resources and theatre time and availability. Whilst questions about non-heart beating donation exist, there has been a 20% increase in non-heart beating organ donation in recent years (DH, 2004).

Living donation

Living donation, whilst not directly related to care of the dying patient, should be mentioned. This occurs when an individual consents to removal of a healthy organ to a person of the same tissue type as themselves. The donor is usually a relative, and the practice is predominant in kidney transplantation, although tissue such as bone marrow can be transplanted. The practice has extended to individuals donating organs to people they do not know and has even occurred via the internet (Olsen, 2007), although to donate an organ for financial gain is illegal in the UK.

THE ROLE OF PALLIATIVE SPECIALISTS IN CARING FOR THE DYING PATIENT

Specialist palliative care services, largely funded by the voluntary sector, have enhanced the quality of care given to dying patients throughout the world and improved our level of knowledge and understanding of the art and science of palliative care (Thomas, 2003). There may still be room for improvement, as those with 'non-cancer' end stage diagnoses such as heart failure, chronic obstructive pulmonary disease, renal failure, neurological disease and dementia, who have equally severe symptoms with similarly poor prognoses, may have reduced access to services or specialist advice (Thomas, 2003). There is also acknowledgement that support for patients living at home with advanced cancer is sometimes poorly coordinated and may not be available over 24 h (Storey *et al.*, 2003). Whilst not denying the substantial role that these organisations play in palliative care delivery in all settings, it could be suggested that a reliance on voluntary funding could be a contributing factor hindering improvements in care. There is also a need for hospital and community-based MDTs to embrace the clinical expertise and experiences of some of these services.

To list and describe organisations that have input into palliative care would be overwhelming and beyond the scope of this text. The role of two prominent organisations in cancer care is described further.

Macmillan Cancer Support

Macmillan Cancer Support is a voluntary-funded organisation founded originally as The Society for the Prevention and Relief of Cancer by Douglas Macmillan in 1911 as a response to him witnessing his father's pain and suffering as a result of cancer. Since its formation, the organisation has contributed significantly to developments in cancer care, making contributions to building hospices, funding nursing and medical posts, and providing multidisciplinary training and education. In 2005, the number of Macmillan multidisciplinary health professionals rose to 3500. The organisation is multifaceted and provides social, emotional, financial and practical support for those with cancer. The involvement of Macmillan professionals should begin at the diagnosis of

cancer and can continue up until death, with continuing support for bereaved families after death.

Marie Curie Cancer Care

Marie Curie Cancer Care was established in 1948 and is now one of the UK's largest health charities. It employs nearly 3000 health-care professionals and provides free direct and indirect care to around 25000 people with cancer annually. The organisation does not focus solely on cancer and helps individuals nearing the end of life through other organ system failure/disease processes. There are three main inter-linking aspects of work: (1) nursing, (2) Marie Curie hospices and (3) research into both cancer and palliative care.

One of the aims of Marie Curie Cancer Care is to allow patients requiring end-of-life care to die at home if this is their wish. Sixty-five per cent of people with cancer want to die at home; at present only about 30% are successful in doing so (Higginson & Sen-Gupta, 2000) This may be because the place of final care for patients with terminal illness is influenced more by resource availability than patient choice (Storey *et al.*, 2003). Marie Curie nurses deliver direct care to patients, providing respite for carers, often overnight. This may often negate the need for hospital admission.

Marie Curie Cancer Care has 10 hospices throughout the UK, offering day therapy, complementary therapies and specialist care.

Other palliative care specialists

There are many individuals who contribute to palliative care both generally and within specific disease frameworks. This includes oncologists, pain specialists and nurses specialising in fields such as upper gastro-intestinal disease, breast care and stoma care. The role of these individuals cannot be understated.

SUPPORT ORGANISATIONS

There are many support organisations that may play a large role in caring for the dying patient; services offered by these organisations can be wide ranging, from direct care provision and advice to providing somebody to talk to.

Some hospice organisations offer a bereavement follow-up service for bereft relatives. Access to the majority of these organisations is usually free and increasingly easy through the internet.

Table 1.5 is a list of some useful organisations and general contact advice; the list is by no means exclusive and any omission is unintentional.

ROLE OF THE HOSPICE IN THE CARE OF THE DYING PATIENT

The concept of hospice care was developed as a reaction against the medical model of disease, diagnosis and cure (Clarke, 2002). Integral to this development process was Dame Cicely Saunders, who has been credited with founding the hospice movement and playing a key role in revolutionising care of the dying in the UK. The first hospice, St Christopher's Hospice in London, opened in

Table 1.5 Support organisations

Organisation	Service provided	Contact
Cancerbackup	Europe's leading cancer information charity, with over 6500 pages of up-to-date cancer information, practical advice and support for cancer patients, their families and carers	www.cancerbackup.org.uk 0808 800 1234
Marie Curie Cancer Care	Marie Curie nurses provide free nursing care to cancer patients and those with other terminal illnesses in their own homes	www.mariecurie.org.uk 0800 716 146.
Macmillan Cancer Support	Practical, medical, emotional and financial support	www.macmillan.org.uk CancerLine 0808 808 2020 Macmillan YouthLine 0808 808 0800

Table 1.5 *Continued*

Organisation	Service provided	Contact
The Samaritans	Confidential, emotional support, 24 h a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide	www.samaritans.org.uk 0845 790 9090
NHS Direct	Telephone and e-health information services day and night direct to the public	www.nhsdirect.nhs.uk 0845 4647
ACT (Association for Children with Life-threatening or Terminal Conditions and their Families)	Information on support services for families whose children have life-threatening or terminal conditions	www.act.org.uk Information line 0117 922 1556
Breast Cancer Care	Support and information for women with breast cancer or other breast-related problems	www.breastcancercare.org.uk Helpline 0808 800 6000
British Red Cross Society	Local services including transport and escort, medical loan and domiciliary care	www.redcross.org.uk 020 7235 5454
Cruse Bereavement Care	Help to people bereaved by death. Free counselling service. Opportunities for contact with others through bereavement support groups and advice	www.crusebereavementcare.org.uk
Hospice Information	Publishes a directory of hospice and palliative care services	www.hospiceinformation.info 0870 903 3903
Sue Ryder Care	Services include long-term care, respite care, symptom control, rehabilitation, day care and domiciliary care	www.suerydercare.org 020 7400 0440

1967. This hospice, and its approach to end-of-life care, became an inspiration to other healthcare areas (Clarke, 2002) and the hospice model of care has grown into a worldwide movement that has greatly influenced care for those with end-stage diseases and cancer, and those requiring end-of-life care. The general philosophy of hospice care is the affirmation of death as a natural part of life, and holistic care is delivered meeting physical, emotional, social and spiritual needs as patients approach the end of life. Hospices are staffed by MDTs, who strive to offer freedom from pain and symptoms as a result of disease, and to provide dignity and peace at the end of life.

There is a general impression that a hospice is a place where people go to die. Evidence refutes this: approximately 50% of patients admitted to a hospice are discharged, the majority of whom are discharged home (National Council for Palliative Care, 2006). This may be because aspects of care, such as symptom control, are specific; sometimes complementary therapies can be offered by hospices and patients may be admitted for these reasons. Respite care and day care is also frequently available.

All hospice care is free of charge, yet many organisations rely upon fundraising and charitable donations to maintain high standards. The hospice philosophy and models of care are adaptable for use in the community and hospital setting; modification of hospice models such as the LCP is one approach to improve palliative care in all settings. The hospice approach to care has also led to ventures such as the hospice at home (National Forum for Hospice at Home, UK, www.hospiceathome.org.uk/), allowing patients to die at home with a comprehensive hospice-based care package. Today the word 'hospice' is synonymous with quality care towards the end of life; the challenge is to transfer that synonymity into all healthcare settings.

CONCLUSION

Meeting the care needs of the dying patient is complex and highly individualised. It is influenced by social, cultural, religious and spiritual factors. Other influences include legal, moral and ethical issues, and the attitudes of care givers themselves.

Maintaining high standards in caring for the dying patient is the responsibility of all the MDT and each individual member

working towards a shared goal of allowing a good death as perceived by that patient and supporting his or her bereft relatives.

Excellent, multilayered communication through all mediums is the key skill required to meet these responsibilities.

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