7.4 Care of the dying person 639

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ESSENTIALS The care a patient receives in the last hours to days of life is im- portant: it has a significant impact on their quality of life and death, and on the psychological well-being of their loved ones and the team delivering care. Most deaths are not sudden or unexpected, but recognition that a patient is dying is challenging. Clinicians’ es- timates of survival are often inaccurate, with a tendency towards over-optimism, yet clinical teams must be able to agree goals and care plans with patients and their loved ones while acknowledging and communicating the uncertainty inherent to prognostication. Shared individualized decision-making is essential: patients must be offered the opportunity to participate in decisions, but a preference not to be involved should be respected. The aim must be to agree an individual plan of care that incorporates the needs and prefer- ences of the person and, as far as it is possible, those close to them. Introduction The care a patient receives in the last hours to days of life has a sig- nificant impact on their quality of life and death, and on the psy- chological well-being of their loved ones and the team delivering care. There is only a small window of opportunity to optimize care and only one chance to ensure that the right care has been delivered in the right place in the right way. Care involves several core com- ponents (see Box 7.4.1) that should be reviewed on a regular basis (Fig. 7.4.1). To achieve this, services must be configured to provide round the clock care to dying patients in all care settings, including their own home. This necessitates adequate training for all multidisciplinary teams providing care to dying people, accessible evidence-based guidance, responsive community services, high-quality facilities in care institutions, and 24-hour access to senior clinicians, expert teams, medication, and equipment. Recognition of dying Recognition that a patient is dying is challenging. It requires inter- pretation of multiple clinical features that are disease- and patient- specific, in an emotionally charged and dynamic context. Clinical teams must be able to agree goals and care plans with patients and their loved ones, while acknowledging and communicating the uncertainty inherent to prognostication. Definitions Several ambiguous terms, including palliative, terminal, and com- fort care, are applied to dying patients. This confuses communica- tion with patients, relatives, and professionals. A person should be described as dying when they are expected to live only for hours to a short number of days. In contrast, the term ‘end of life’ applies from the point a person is believed to be entering the last months to a year of life.

Recognition of dying is fundamental to good care in the last days of life (see Box 7.4.2). The process Most deaths are not sudden or unexpected. They are the conse- quence of progressive incurable illnesses, multimorbidity, and frailty. For such patients, recognition of dying should have been preceded by exploration of prognosis and treatment goals earlier in their disease trajectory. If early communication has not occurred, clinicians might be confronted by a patient who is deteriorating and at risk of dying with whom they are unfamiliar, who has not been engaged in advance care planning, and who might lack capacity to participate in decisions. Even in situations when a patient is known to be ter- minally ill and some planning has taken place, they might also be receiving treatment for a potentially reversible intercurrent illness. The associated uncertainty further complicates recognition of dying and subsequent decision-making. 7.4 Care of the dying person Suzanne Kite and Adam Hurlow Box 7.4.1 Requirements for high-quality care of the dying patient • Timely recognition that a patient is likely to die in hours to days • Sensitive communication with the dying person and those close to them • The opportunity for the patient and their loved ones to participate in decision-making • The agreement and implementation of individualized and realistic treatment goals and care plans • Practical and emotional support for the dying person and their family and friends • Regular holistic review of the dying person and their plan of care

640 Section 7 Pain and palliative care This illustrates the need for thorough clinical assessment and in- vestigation, leadership from senior clinicians expert in treatment of a patient’s underlying condition(s), high-quality handover, and engagement of the multidisciplinary team in establishing the cause of deterioration and recognition of dying. Services should be con- figured to ensure this is possible at any given time. Recognition of dying involves the identification of deteriorating health and a judgement that if the physiological processes under- pinning it are not—or cannot—be addressed, then they are likely to be fatal within hours to days (see Fig. 7.4.2). It is essential that the right professionals and expertise are engaged in establishing if attempts to reverse clinical deterioration are likely to work and are consistent with a patient’s wishes. The recognition that a patient might be dying imminently is one step in a cycle of assessment, re-assessment, and decision-making. Prognostication in the last days of life Clinicians’ estimates of survival are often inaccurate, with a ten- dency towards over-optimism. Accuracy is improved if clinical judgement is combined with explicit consideration of performance status and relevant clinical and biochemical markers (Box 7.4.3). The health of an individual patient can fluctuate and the rate and degree of change in the patient’s overall condition is informative. Repeat prognostic assessment, including serial application of a prognostic tool, has been shown to improve accuracy beyond esti- mates derived from a single assessment. Prognostic tools Unfortunately there is a paucity of reliable, adequately validated prognostic tools that accurately predict survival of hours to days. No one tool or approach is likely to be applicable across mixed patient populations. However, the Palliative Performance Scale (PPS) is a nondisease-specific tool based on functional and disease status, oral intake, and conscious level that might be a useful ad- junct to experienced clinical judgement. The PPS has been applied to patients with cancer and noncancer diagnoses in various settings. For patients scoring less than 20% on the PPS, seven-day mortality ranged between 50 and 99%. Survival continued to fall as scores reduced; 85% of patients scoring 10% died within three days. However, even applying the PPS, clinicians’ estimates were accurate in only 20% of patients demonstrating the usual tendency to overestimate survival. Decision-making Clinicians, patients, and their loved ones need to understand that survival estimates are provisional and subject to considerable un- certainty. This necessitates robust clinical assessment by senior clinicians,

multidisciplinary team engagement, regular review, and high-quality communication with patients and those close to them. Shared individualized decision-making is essential. Patients must be offered the opportunity to participate in decisions but a preference not to be involved should be respected. The involve- ment of loved ones in significant discussions might be helpful for Recognize dying Communicate this to your patient, those close to them and the MDT Offer your patient and those close to them the opportunity to participate in care planning Review your patient regularly Support your patient, their family and friends Implement an individualized care plan Fig. 7.4.1 Care involves several core components that should be reviewed on a regular basis. Adapted from Leadership Alliance for Care of Dying People (2014). One Chance to get it Right. UK Government Publications Gateway Reference 01509. Box 7.4.2 Reasons why recognition of dying is important • Patients and those close to them may want prognostic information and should be offered the opportunity to understand that death is imminent. • An understanding of prognosis may help patients and relatives to appraise care and treatment options including place of death. • It is the last opportunity for loved ones to say goodbye. • An understanding that their family or friend is dying may help the bereaved psychologically and emotionally process their grief. • It is an opportunity to review care plans, manage symptoms, evaluate the benefit of interventions and provide resources (parking permits, facilities to stay overnight in hospital) to support friends and family. • It is likely to be the last opportunity to help a patient achieve their preferred place of death and related preferences.

7.4 Care of the dying person 641 patients and the views of those people close to patients who lack capacity are important in determining what their wishes might have been. However, their views do not outweigh those of a patient with capacity. Those close to the patient should be reassured that, when a patient lacks capacity, the burden of responsibility for deci- sions to forgo clinically ineffective treatment or other best interests decisions, lies with the treating team. Recognition of dying embodies a process of thorough clinical as- sessment in which patients' and relatives' views and understanding are elicited, their needs defined, realistic goals agreed, probable outcomes explained, and management plans implemented and re- vised in light of changing circumstances. Communication Good communication with people who are dying can have a profound effect on the quality of the patient's remaining life, and for the bereavement and memories of those close to them. Sensitive communication that time is now very short, and of what might be expected to happen, helps to build the trusting Recognize your patient's health is deteriorating over hours to days. Establish if they would consider life-prolonging treatment. If they would consider treatment, assess and investigate the cause of deterioration. Assess the likelihood that the deterioration can be delayed, halted, or reversed. Consider the benefits and burdens of treatment with your patient and/or those close to them. If:

1. clinical deterioration cannot be forestalled or
2. the patient has declined treatment or
3. treatment is not in their best interests Your patient is at risk of dying within hours to days. Regularly review your patient's condition, prognosis, and care plan, revising treatment in light of clinical developments. Fig. 7.4.2 Recognition of dying involves the identification of deteriorating health and a judgement that if the physiological processes underpinning it are not, or cannot be, addressed then these are likely to be fatal within hours to days. Box 7.4.3 Features suggesting an increased risk of imminent death • Elevated and escalating medical early warning scores/a deterior- ation in physiological observations • Progressive

impairment of mobility to the point that a patient is in bed all the time • Progressive functional impairment to the point that a patient is fully dependent for all personal care • Progressive reduction in oral nutritional intake to the point that a patient can take only minimal amounts of fluid and may be unable to swallow their own saliva • Progressive impairment of consciousness • Increasing confusion/delirium • Agonal breathing with alternating tachypnoea, apnoea, and gasping • The absence of any reversible cause for deteriorating health • Diagnosis of a life-limiting illness with evidence of disease progression • Progressive deterioration in biochemical markers linked to specific disease states • Reduced urine output • Increasing rate and magnitude of clinical deterioration

642 Section 7 Pain and palliative care relationships that patients need at this most vulnerable time, and supports them to share concerns and to fulfil wishes. This includes choosing who they want to be with, and where, and being involved in decisions about their plan of care. Conversely, poor communication can compound fear and anxiety, leaving patients and those close to them feeling scared and isolated. Good communication requires sensitivity, skill, and planning (see Box 7.4.4). The healthcare team needs to reflect on what needs to be com- municated, and by whom. What information needs to be shared? What do the patient and those close to them need to be consulted about, and how can they best be involved in decision-making? (Box 7.4.5). Not all patients want honest and open discussion, and this should be respected. For others, physical factors such as fatigue, frailty, cognitive impairment including delirium, and shortness of breath, might limit their capacity to participate. An assessment needs to be made for each individual, for each element of communication, with the rationale for communication and decision-making recorded in the clinical case notes. Where patients have capacity, their permission must be sought for the involvement of others. Where patients lack capacity, all those involved must be clear that the basis for decision-making is that of best interests. Discussions around dying are challenging for all of us, exposing our own beliefs and fears. Doctors should question any assump- tions that they find themselves making, particularly when these are limiting communication with a patient who has the capacity to be involved. Even when well informed, relatives can feel that they are imposing a ‘death sentence’ on their relative by agreeing to dis- continuation of treatment or a ‘Do Not Attempt Cardiopulmonary Resuscitation’ (DNACPR) status, and reassurance must be given that this is not the case. The communication skills required for the care of the dying are the same as those needed throughout Box 7.4.4 An approach to sensitive communication about dying How we communicate is as important as what we say. The usual principles of good communication apply. Prepare by: • planning what needs to be discussed • who needs to be present, including another member of staff other than yourself • establishing in advance if there are specific people a patient would like to be present for significant conversations • considering whether additional support is required, for example, for people with learning disabilities, and for those requiring an interpreter • finding a suitable private place where disruptions can be kept to a minimum • being attentive for verbal and nonverbal patient cues indicating a desire to discuss, or refrain from, sensitive issues • adopting a comfortable posture at the same level as everyone else Take particular care that communication is: • open and honest • clear and understandable, using plain language • respectful in pace and tone • empathic, but allowing for silence • responsive to what the person and those close to them feel able to discuss at that time • based on shared decision-making to the greatest possible extent Check understanding of the information being communicated. Encourage questions. Where consensus is lacking: • discuss differences of opinion openly • consider whether

additional advice is necessary • offer your availability and/or that of the team for further discussion • consider whether a second opinion would be beneficial • document discussions carefully Be aware of the impact of the discussion, and take care of yourself: • debrief with another team member, and, if necessary, seek support outside the immediate clinical environment. Box 7.4.5 Points to consider in the initial discussion • The possibility that a person may die within the next few hours/ days, and why you think this. • The cause and impact of any symptoms that the patient may cur- rently be experiencing. • Reassurance about expected bodily changes such as altered breathing patterns that could otherwise be alarming to family and friends. • How uncertainty will be managed. • How and when death might occur. • Identification of key decision-makers and people to consult, including those close to the patient, and legal representatives as appropriate. • The name of the senior responsible clinician and nurse. • How the patient/family can be involved in care planning to the degree that they wish. • Where a patient lacks capacity, the role of advance care plans, healthcare proxies, and how best interests decisions will be made. • Preferred place of care and death, with consideration of the benefits and limitations of differing settings for the individual. • Patients' and family's questions and concerns: address as appropriate throughout, and again before bringing the discussion to a close. Care planning: Review all interventions and care to identify which offer benefit to the patient. • CPR usually is of no medical benefit in these circumstances and a 'do not attempt cardiopulmonary resuscitation' decision should usually be made and the rationale explained. • Does the patient have a cardioverter defibrillator that requires deactivation? • Anticipation of the patient's needs and symptoms, including the pre- scription of anticipatory medications. • How and why medications may be given, and the rationale for using a syringe pump if required. • How those close to the patient can be involved in providing care. • Support for those close to the patient, including visiting & car parking arrangements; toilets; refreshments; overnight accommodation Communication is a process: • Explain how the dying person's care will be reviewed and when • Offer your availability and/or that of the team Document the discussion in a place accessible to all those caring for the patient, including a record of those present.

7.4 Care of the dying person 643 healthcare. Even highly experienced communicators, however, can find discussions around care at the end of life difficult for a variety of reasons. Sometimes this difficulty is in finding the words to convey upsetting and often complex information to people at a vulnerable time with sensitivity, skill, and humility. Being ad- equately prepared is crucial. Ensure that enough time is allowed for this, and that the clinician is prepared emotionally themselves. For example, the impact of a recent personal loss of their own might mean that a staff member is not the best person to lead the discussion at this time, or might need support to do so. Consider talking through the plan beforehand, and debriefing afterwards, with a colleague or senior clinician or nurse. Taking time away from the bedside to think through helpful phrases, and phrases to avoid, can be invaluable (Box 7.4.6). Observing more ex- perienced colleagues in similar situations may also be useful. Individual care plan Once it is recognized that a person is likely to die within the next few days or hours, an individual plan of care should be agreed incorporating the needs and preferences of the person and, as far as it is possible, those close to them. Such a plan includes food and drink, symptom management, and psychosocial and spiritual support, in the context of the patient's preference for place of care. Regular review and responsiveness to change in the patient's condition and needs should be part of the care plan. Compassion and sensitivity are vital in planning and providing care, and in considering how this individual's dignity can best be respected. The principles of symptom management are the same as at any stage of illness, but the priority is comfort and keeping unneces- sary disruption to a minimum. The patient's energy level will dic- tate the degree to which they can participate directly in assessment and planning (see Boxes 7.4.7 and 7.4.8). For current symptoms, review the efficacy and route of admin- istration of medication and consider whether a nonoral (usually subcutaneous route) is required (Box 7.4.9). Prescribe appropriate medication as needed for symptoms that are common in the last hours and days of life, and which may develop, to ensure timely administration (see Box 7.4.10). It is important to review a patient's current management on an intervention by intervention basis. Some pre-existing treatments might continue to be of benefit and contribute to symptom man- agement. For instance, insulin therapy, transdermal dopamine Box 7.4.6 Finding the words Use open questions to explore insight and understanding, and to open a discussion, such as: 'How do you think things are going?' 'How do you find your father today?' 'Has your husband expressed any wishes about where he would like to be cared for?' Closed questions can be used in response to cues or to explore issues or concerns, for example: 'Are you concerned that you will be in pain?' 'Are you worried that your mother might be thirsty?' Some phrases to avoid include: 'There is nothing more that we can do' (it is always possible to do something). 'I know what you're going through/how you feel' (you don't) 'It wouldn't be worth (doing that intervention)' or 'it would be futile' (can be taken to mean that the patient is not worthy, rather than that the treatment confers no medical benefit) Box 7.4.7 Assessment of the patient's needs This requires collaboration between the patient, those close to them, and the healthcare team: • Tailor questions to the patient's condition. • Ask specifically about symptoms likely to be present—questions re- quiring 'yes' and 'no' answers may be easier for an exhausted patient to answer. • Seek the observations of others close to the patient and other mem- bers of the team. • Look for nonverbal cues of distress. • Focused physical examination on any site of pain, the mouth, pres- sure areas, and other areas where clinical assessment suggests that there may be a problem. • Enquire about spiritual, religious, and faith requirements. • Address fears, and misapprehensions as necessary. • Take time to talk to the patient's family and those important to them: to offer reassurance, and as an opportunity to answer their questions and to address their own comfort and spiritual needs. Regular contact is appreciated, even when the patient is well-settled. Refer to specialist palliative care team early if you anticipate difficulty in ensuring the patient's comfort. Box 7.4.8 Management of patients' symptoms and promoting comfort • Aim to control the symptoms which are distressing the patient. • Discontinue medication, investigations, and routine observations unrelated to comfort measures, explaining rationale to patient and family. • Medication may need to be given subcutaneously as swallowing de- teriorates (see Box 7.4.6). • Prescribe as required (prn) medication for anticipated symptoms such as anxiety, agitation, pain, seizures, or noisy rattling breathing. • Mouthcare is very important. Patients often have a dry mouth as a result of mouth breathing, drug side effects (opiates, anticholiner- gics), compounded by poor oral fluid intake. The patient's mouth should be kept clean and moist with the frequent application (at least hourly) of foam sticks soaked in water or Biotene gel, with dry lips treated with Biotene. • Skincare includes careful positioning and regular turning, gentle massage, and an appropriate mattress. • Urinary retention is a common cause of discomfort and/or agitation. Assess whether a urinary catheter is required. • Speak gently to the patient when you approach them, and explain what you are going to do. Even if the patient appears asleep or un- conscious, they may be able to hear you. • Review regularly: nurses should review the patient regularly throughout the day, with the frequency dependent on individual patient need. Senior clinical review should be at least daily if the patient is settled, and more frequently if the patient is uncom- fortable, if their condition changes, or family or nursing staff raise concerns.

agonists for Parkinson’s disease, and supplemental oxygen can pro- vide ongoing management of concurrent conditions and promote comfort for some patients as they die. Avoid blanket discontinu- ation of current therapy. As far as is possible, explain to the patient and those close to them what the dying person might experience, and approaches to managing symptoms and comfort, in particular: Food and drink. Patients and families often wish to discuss how the dying person’s hydration and nutritional needs will be met once their oral intake becomes limited. No correlation has been found between biochemical evidence of dehydration and the symptom of dry mouth, and there is the risk with parenteral hydration of per- ipheral and pulmonary oedema. There is no conclusive evidence of benefit/harms to support either the use or withholding of paren- teral fluids in dying people. In practice, subcutaneous or intravenous fluids can be used when a patient is unable to take sufficient oral fluid and they complain of thirst, or consideration of their particular physiology suggests that Box 7.4.9 Background analgesia Patients who had been swallowing oral analgesia up to this point, but can now no longer do so, will need to continue this through an alterna- tive route; for example, a patient who has been taking modified-release morphine 30 mg 12-hourly orally may be converted to: • Subcutaneous morphine: conversion rate 2:1 (i.e. morphine 30 mg by subcutaneous infusion over 24 h). • Rectal morphine: conversion rate 1:1 (i.e. morphine 10 mg 4-hourly) suppositories or morphine 30 mg 12-hourly modified-release suppositories Please seek specialist advice for other opioid conversions, and where patients already have transdermal opioid patches if you are unsure what to do. Transdermal opioid patches (i.e. fentanyl and buprenorphine) are usually continued, but not titrated further—check skin adherence and ensure that they are sited in a clearly visible and accessible place. Additional background analgesia can be provided by either of the routes mentioned here, with the dose determined by review of the efficacy and frequency of the dose of prn medication received. Box 7.4.10 Anticipatory management of common symptoms Remember to specify the indication on the prescription and explain the rationale to patient and family. Follow local guidance where available. Seek advice from the palliative care team or pharmacy if unsure of what to do. Ensure that symptom response to medication is assessed and recorded, with medical review if symptoms persist or several doses are required. Indication Management and as required (prn) medication. Pain For patients already on opioid analgesia, see Box 7.4.9. If opioid naive: morphine 2.5–5 mg SC, with a lower dose in older people, the frail, and those with renal impairment (but eGFR >50). If morphine contraindicated or eGFR <50, consider oxycodone 2 mg SC. For patients with eGFR <10, seek specialist advice. Follow local palliative care policy on prescription of prn opioids regarding frequency and maximum daily dose. Review use of prn medication: if two or more doses used with good effect within 24 hours, consider continuous subcutaneous infusion. Breathlessness Assess the cause, treat specific conditions if this will aid comfort. Consider nonpharmacological management (e.g. positioning, facial cooling with a fan, calming presence, relaxation, meeting spiritual needs). If drug management is required: For those already receiving an opioid for breathlessness, switch to subcutaneous route by SC injection or continuous subcutaneous infusion (see Box 7.4.9). If opioid naive, follow advice given for management of pain. Restlessness/agitation Carefully assess the patient for cause/s such as pain, urinary retention, constipation, delirium, and anxiety. Manage specific causes as appropriate, provide reassurance and conducive environment (quiet, well lit, and so on), and company, music, and religious/faith/spiritual support as appropriate for this individual. If drugs are required, consider: For delirium: consider haloperidol-seek specialist advice as necessary. For anxiolysis or sedation: benzodiazepines orally or subcutaneously, for example, oral diazepam, or midazolam 2.5–5 mg one off SC injection, or 5–10 mg over 24 h by subcutaneous infusion. Nausea and vomiting Assess likely cause and manage appropriately. Noisy, rattling breathing Assess and address the source: salivary, bronchial, or gastric. Infected bronchial secretions are unlikely to respond to antisecretory medication. Exclude fluid overload and review/adjust clinically assisted hydration as necessary. Try re-positioning, and consider gentle suctioning if appropriate and tolerated (nursing staff can advise). Offer explanation and set realistic expectations depending on cause. Noisy breathing can upset friends and family. If is not causing the patient distress or discomfort offer reassurance that it is not harmful. If drugs required, consider subcutaneous infusion of: hyoscine butylbromide 20–60 mg over 24 h or glycopyrronium 400–800 micrograms over 24 h hyoscine hydrobromide is also used but may cause additional drowsiness and paradoxical agitation.

7.4 Care of the dying person 645 this might be a problem. However, conditions that strongly predis- pose to fluid overload, such as heart or renal failure, would usually be contraindications. Careful explanation of the potential bene- fits and harms of parenteral hydration is required. Where there is genuine uncertainty about the value of fluid therapy, and there is strong desire for it, a monitored therapeutic trial is reasonable. Noisy rattling breathing might occur within hours or days of death as the dying person becomes unable to clear secretions by coughing and swallowing. This ‘rattle’ rarely distresses the patient but can be very distressing for others (see guidance in Box 7.4.10) Restlessness is often multifactorial, and careful assessment and explanation is necessary (Box 7.4.10). Be careful to explain and document the specific indications and dose of any sedative drugs. Recent literature reviews do not support the concern that potentially sedative medication, when correctly used to manage symptoms, hastens death. Particularly careful consideration and communi- cation are required on the rare occasions where the intention is to deeply sedate the patient (e.g. to manage intractable seizures), and specialist advice is recommended in these circumstances. Care in different settings. Patients in hospital may wish to be dis- charged to die at home. This requires careful planning, with the family and community services needing as much time as possible to prepare. However, it might be possible to effect this within hours. Involve community nursing teams and the general practitioner, and social services and palliative care team if appropriate, at an early stage. Managing uncertainty. Some patients who appear to be imminently dying do recover. Be vigilant to improvements in the patient’s con- dition, and be prepared to adapt the management plan accordingly. Reassure the family that the patient will be kept under close review. Organ and tissue donation. People with advanced progressive illnesses, including cancer, and dying patients being cared for in an intensive care unit, might be eligible for eye and tissue donation. Discussing a person’s wishes in this regard supports the goals of those wishing to be considered for donation. Donors are assessed on an individual basis, and relevant organ and tissue coordinators will be able to advise. Verification of death Death can be described as the ‘irreversible loss of the capacity for consciousness combined with the irreversible loss of the capacity to breathe’. These conditions are met in both irreversible brain stem failure and following cardiorespiratory arrest. A clinician can only proceed with the diagnosis of death if cardiopulmonary resuscitation (CPR) is unwanted, has failed, or is of no clinical or overall benefit. In the absence of signs pathognomonic of death (hypostasis, rigor mortis) diagnosis following cardiorespiratory arrest requires identification of ‘the simultaneous and irreversible onset of apnoea and unconsciousness in the absence of the circulation’. In practice, cardiorespiratory arrest can be confirmed by palpation of the central pulse, auscultation of the heart and lungs, and observation for respiratory effort over five continuous minutes. Death can be confirmed though demonstration of absent pupillary response to light, corneal reflexes, and motor response to supraorbital pressure. Any spontaneous transient return of cardiorespiratory effort should prompt a further five minute period of observation. Certification of death Completion of formal documentation describing the cause of a person’s death serves a range of purposes:

1. It allows a legal record of the fact of death to be established; enabling the next of kin to arrange disposal of the deceased’s body and to settle their estate.
2. It provides those close to the deceased with a formal written ex- planation of why their loved one died, which might be psycho- logically important and also relevant to their health and that of their offspring.
3. It provides the mortality data that are vital for public health and a strategic approach to managing healthcare resources. The clinician certifying death should have been involved in the care of the patient during the illness that led to death, and have access to the records necessary to accurately establish the cause of death. The cause of death should be certified according to World Health Organization recommendations. When completing a cause of death, describe a diagnosis or diag- noses concisely but with relevant detail. For instance, provide the histological type and anatomical site of a cancer or the type of diabetes mellitus. Consider using language family and friends will understand and offering verbal explanation at the time the certifi- cate is provided. If the person collecting the death certificate has not been present during the final illness, the diagnosis may be unexpected and will require sensitive communication. Deaths which might be the result of accident, suicide, violence or industrial disease, occur under other specific circumstances, or for which the cause of death is unknown require referral to a coroner for consideration of further investigation. If it is known prior to death that a patient must be referred to a coroner, the patient and those close to them should be made aware of this. Emphasize that it is not dependent upon the individual clinician’s discretion. This minimizes the shock of referral and prepares the bereaved for potential delays in death certification and burial. Care after death The provision of individualized care for deceased patients and those close to them is a fundamental part of holistic care at the end of life. Dying patients need to be confident that their preferences and beliefs will be adhered to by the teams providing care after their death. Both prebereavement care provided to friends and family while a patient is alive and guidance and support after death are important for promoting successful adaptation to bereavement (Boxes 7.4.11 and 7.4.12). The recently bereaved might be unable to process or retain infor- mation and will need clear, and possibly repeated, guidance about complex or unfamiliar processes. Information should be provided orally and in writing. Social, cultural, and religious considerations Personal, religious, or cultural practices relevant to care after death should be established and planned for prior to death. Clinicians

646 Section 7 Pain and palliative care should have working knowledge of the requirements of the main faith and cultural groups in their locality and know how to access guidance. It is dangerous to assume that a patient has specific beliefs on the basis of sociocultural heritage. They might not be adherent to the tenets of the dominant, or indeed any, faith. Some religions re- quire burial within 24 hours of death, and rapid repatriation might be planned. Preparations should be made for this (Box 7.4.13). Uncertainty, controversy, and future developments The recognition and care of dying patients remains the focus of controversy and subject to considerable societal scrutiny. Concerns

have been raised about the quality of communication with patients and families, the rigour of clinical decision-making, premature discontinuation of treatment, the use of care pathways, the need for individualized care, and the potential side effects of medication used for symptom management. There is a recognized need to improve the evidence base under- pinning care for dying patients with a focus on high-quality research addressing significant areas of uncertainty including prognostication, symptom management, training for professionals and informal carers, and the organization of care and services. A robust research agenda is essential to ensure that the needs of all patients in the last days of life are met irrespective of diag- nosis, care setting, and the hour and the day that care is required. This will impact upon the experience of the dying person and more enduringly those who survive them. In the words of Dame Cicely Saunders, founder of the modern hospice movement: ‘How people die remains in the memory of those who live on.’

FURTHER READING Academy of Royal Medical Colleges (2008). A Code of Practice for Diagnosis and Confirmation of Death. http://www.aomrc.org.uk/ publications/reports-guidance/ukdec-reports-and-guidance/ code-practice-diagnosis-confirmation-death/ Beller EM, et al. (2015). Palliative pharmacological sedation for ter- minally ill adults. Cochrane Database Syst Rev, 1, CD010206. Downing M, et al. (2007). Meta-analysis of survival prediction with Palliative Performance Scale. J Palliat Care, 23, 245–54. General Medical Council (2010). Treatment and Care Towards the End of Life: Good Practice in Decision Making. https://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp Glare PA, Sinclair CT (2008). Palliative medicine review: prognosti- cation. J Palliat Med, 11, 84–103. Good P, et al. (2014). Medically assisted hydration for adult palliative care patients. Cochrane Database Syst Rev, 4, CD006273. Hung CY, et al. (2014). Magnitude of score change for the palliative prognostic index for survival prediction in patients with poor prognostic terminal cancer. Support Care Cancer, 22, 2725–31. Knauft E, et al. (2005). Barriers and facilitators to end-of-life commu- nication for patients with COPD. Chest, 127, 2188–96. Lau F, et al. (2007). A systematic review of prognostic tools for estimating survival time in palliative care. J Palliat Care, 23, 93–111. Leadership Alliance for Care of Dying People (2014). One chance to get it right. UK Government Publications Gateway, Reference 01509. National Institute of Health and Care Excellence (2015). Care of Dying Adults in the Last Days of Life. NICE guideline [NG31]. https://www.nice.org.uk/guidance/ng31?unlid=3733136482016228163854 Parker SM, et al. (2007). A systematic review of prognostic/end- of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the con- tent, style, and timing of information. J Pain Symptom Manage, 34, 81–93. Su J, et al. (2015). Do repeated assessments of performance status im- prove predictions for risk of death among patients with cancer? A population-based cohort study. Palliat Med, 29, 547–53. Wilson F, Gott M, Ingleton C (2013). Perceived risks around choice and decision making at end of life: a literature review. Palliat Med, 27, 38–53. World Health Organization (1979). Medical certification of cause of death, 4th edition. World Health Organization, Geneva. Wright AA, et al. (2008). Association between end-of-life discussions patient mental health, medical care near death and caregiver be- reavement adjustment. J Am Med Assoc, 14, 1665–73. Box 7.4.12 Care needs in the weeks after death • A personalized letter of condolence from the team involved in care of the dying person • An opportunity to discuss unresolved questions or concerns with a senior clinician • Information about bereavement support, counselling, and psycho- logical care • Consider need for a formal assessment of bereavement needs Box 7.4.13 Preparation for patients requiring rapid burial • Ensure access to death certificates around the clock • Ensure clinicians on duty are able to complete the necessary docu- mentation (e.g. they have seen a patient prior to death and can state the cause of death) •

Establish details of the burial contacts/societies within local faith/ cultural groups Box 7.4.11 Care needs in the hours to days after death • Sensitively timed verification, confirmation, and certification of death • Sensitive communication that the patient has died • An opportunity for the bereaved to ask questions about events leading to death • Sensitive communication about bodily changes and care processes after death • Opportunities for the bereaved to spend time alone with the deceased person, to participate in personal care, and view the deceased after transfer to a mortuary • Personal care within 2–4 hours including positioning, washing, mouth and wound care, dressing, and handling of valuable property • Explanation of procedures for collection of a death certificate, registration of death, and other processes • Information about bereavement support

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