6.11 Promotion of dignity in the life and death of

6.11 Promotion of dignity in the life and death of older patients 612

ESSENTIALS Respect for the dignity of patients is a traditional part of medical codes. Dignified care is key to a holistic person-centred approach, with participation of the individual, communication, and respect. Nurses and doctors recognize lack of dignity in depersonalized care, treating the person as an object, humiliation, abuse, and invisibility. Older people regard dignity as critically important in their care. This relates to issues around privacy, courteousness, respect for the individual, and consideration about choices related to care, and to respect for cultural or religious needs. Assuring dignity requires the sensitive addressing of basic needs and the promotion of inclusivity and participation, with recognition that even in the presence of some impairment of cognition the wishes and views of the patient remain central to decision-making. Elder abuse can be defined as a single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person. These acts may be through neglect, or physical or psycho- logical abuse, or sexual assault. The precise prevalence of abuse is uncertain, but it occurs sufficiently frequently that all clinicians who come into contact with older people are likely to encounter it. Recognizing when people enter the last year of their life is im- portant to achieve the right focus of care for older people. The rate of functional decline, measured as deteriorating performance status, is the most reliable indicator of prognosis in patients with ad- vanced illness, regardless of diagnosis. A diagnosis of dying should prompt timely appropriate discussions with patient (when possible) and family members, with explanation of the transition of the goals of care from ‘cure’ to ‘maintaining comfort’. Anticipatory care plan- ning is key to ensuring that patients live and die in the manner that they wish. Dignity A philosophical perspective Philosophically the concept of dignity dates to at least the time of Aristotle (384–322 BC), who linked it to a sense of being worthy of respect; he regarded it as the desired state between an excess of servility and of self-importance. Subsequently, Kant in the 18th century defined dignity as that quality possessed by things which have value but cannot be traded,

and which are above price. For Kant, the concept of dignity related to the human character- istics of rationality and autonomy. Although Kant referred to the ‘intrinsic value’ of humans, this is linked in his writing to the possession of autonomy. More recent philosophers have also identified autonomy as an important factor in dignity, for example, describing a foolish choice as having the potential to cause the individual to lack dignity. The concept of autonomy as central to dignity is challenged by others, who see it as one of the values but not the only value important in dignity, and who recognize the importance of dignity even when autonomy is lacking. A well-reported example of the tension which can arise be- tween dignity and autonomy is the case (which occurred as recently as the 1990s) of the French dwarf who was paid to be thrown in a drinking game. The local town council ruled that this was an insult to human dignity, but the dwarf in question appealed against the judgement saying they had deprived him of his livelihood and he ought to be allowed to make autonomous decisions for himself. The following concepts of dignity have been described which are helpful in considering dignity in the context of healthcare. Nordenfelt describes intrinsic and contingent value, and divides the latter into four varieties of dignity (Box 6.11.1). 6.11 Promotion of dignity in the life and death of older patients Eileen Burns and Claire Scampion Box 6.11.1 Dignity • The dignity of Menschenwurde—the dignity all humans have simply by virtue of being human. • Dignity of merit—dignity of ‘office holding’, or as a consequence of having earned merit, for example, a hereditary monarch. • Dignity of moral stature—dignity based on the actions or omissions of an individual, for example, a local community leader. • Dignity of personal identity—related to concepts of self-respect, integrity, autonomy, and inclusion. This can be taken away when someone is insulted or humiliated, for example, a school child sent to stand in the corner.

6.11 Promotion of dignity in the life and death of older patients 613 The meaning of dignity in a healthcare setting Actions of others can be seen to either enhance or reduce another’s dignity. In the context of a care setting, the relationship may in- clude one party (e.g. the doctor or nurse) holding a position of dominance. Dignity can be respected or violated in many ways, due to acts or omissions of staff (Box 6.11.2). Professional views of what constitutes undignified care accord with these views: nurses and doctors recognize lack of dignity in depersonalized care, treating the person as an object, humiliation, abuse, and invisibility. Dignified care is key to a holistic person-centred approach, with participation of the individual, communi- cation, and respect. The role of dignity in the code of conduct of doctors and other healthcare professionals Respect for the dignity of patients is a traditional part of medical and nursing codes. The Hippocratic oath requires those who swear it to respect those who require treatment, regardless of gender or status, and to do so with justice (Box 6.11.3 and Fig. 6.11.1). In many medical schools, updated versions of the Hippocratic oath are sworn, including vows not to alter one’s practice on the basis of the patient’s race, nationality, religion, sex, socioeconomic standing, or sexual orientation. Others include assurances of the physician’s accountability to his or her patients, protection of patients’ autonomy, and informed consent or assistance with decision-making. Both the UK Royal College of Nursing and the International Nursing Code emphasize the respect of the dignity of the individual in their care as a core quality of the nurse. Views of older people and their families about dignity in healthcare Within the healthcare context, the concepts of ‘Menchenwurde’ (i.e. respect for all humans as a consequence of their humanity) identifies that we should treat the unconscious, demented, or de- lirious patient in the same way as any other patient with respect, tolerance, and empathy. Older people regard dignity as critically important in their care. Although philosophers may struggle to define the term,

patients and their relatives are clear that in the context of a healthcare envir- onment it relates to issues around privacy, courteousness, respect for the individual, and consideration about choices related to care, and to respect for cultural or religious needs (Box 6.11.4). Box 6.11.2 A taxonomy of possible transgressions of dignity • Not being seen: when someone is disregarded or unheard—the pa- tient calling for the nurse; the relative trying to catch the eye of the doctor. • Being seen, but only as member of a group (e.g. as a woman, an old person, and so on). Group membership can be a source of pride, but if the treatment of the group is disadvantageous (e.g. delayed attention to a referral from a 'geriatrics' ward), then the dignity of the individual is diminished. • Injuries to dignity from violations of personal space: if permission is not gained there is substantial risk of violation to dignity in the healthcare setting. An example may be the disregard for a wish for privacy in the areas of washing, dressing, or using a toilet. • Humiliation: in this setting, dignity is injured by the singling out of a subject for criticism. An inappropriate response from healthcare staff to a delirious patient or one who has suffered an episode of incontin- ence can easily be perceived as humiliation. Box 6.11.3 The Hippocratic oath ' . . . Whatever houses I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular of sexual relations with both female and male persons, be they free or slaves . . . ' (translated from the Greek by Edelstein L. The Hippocratic oath: Text, translation and interpretation. In: Temkin O, Temkin CL, eds. Ancient medicine: Selected papers of Ludwig Edelstein. Baltimore: Johns Hopkins University Press, 1967:
3-64. Reprinted by permission of Johns Hopkins University Press.) Fig. 6.11.1 Fragment of the Hippocratic oath on papyrus from the
3rd century. Wellcome Library, London. Box 6.11.4 Issues highlighted by patient and carers after hospital discharge in the United Kingdom • Being treated as an individual • Help with eating and drinking • Help with toileting • Privacy in care: keeping curtains closed, private rooms, informa- tion being kept private • Being addressed appropriately by staff (avoidance of inappro- priate use of endearments such as 'love', 'dear') • Maintaining respectable appearance—attention to clothing, grooming • Stimulation—this was especially a concern for care home residents or those living alone in their own home

 The challenge to dignity in the care of older people in the acute hospital Research into the experience of care in acute hospitals has iden- tified several possible barriers to the provision of dignified care (Box 6.11.5). The view that hospitals are not the right places for older people fails to recognize that older people are the main users of healthcare. Thus, the physical environment, staff skills, and education and or- ganizational processes are often not aligned to the needs of the older people using the hospital facilities. For people with dementia, appropriately designed environ- ments can: • promote independence • reduce the incidence of agitation and challenging behaviour and the prescription of antipsychotic medication • improve nutrition and hydration • increase engagement in meaningful activities • encourage greater carer involvement • improve staff morale, recruitment, and retention Careful ward design with attention to colour coding of bays, ad- equate clear signage, safe walking spaces, and communal areas can enhance dignity. Adequate room for equipment required for care (such as hoists), gender-specific washing and toileting facilities, all promote dignity in care. Other factors important to the promotion of dignity are staff education about specific aspects of care of older people including those with dementia, and the engendering of a culture which values and promotes courteous and respectful communication and inter- actions with patients. A focus on 'targets' may have unintended consequences that make dignified care more difficult to achieve. These may include: •

Frequent ward moves in order to allow access for new patients presenting to hospital, or because of ‘specialty bed’ requirements, with loss of the development of a relationship between staff and patients, central to personal care. • A blanket policy of the use of isolation rooms with the aim of re- ducing risk of infection, without recognition that the risk of falls is increased by the use of side rooms, nor with a recognition of the risk of lack of access to stimulation and to care when needed. Dignity and safety may be compromised if an individual assess- ment of risk and benefit is not made. • Financial targets may restrict staffing levels and ‘skill mix’, ren- dering the provision of timely and appropriate care difficult. If staff cannot meet the needs of patients—especially around eating and drinking, washing, dressing, and toileting—dignity is compromised. ‘Seeing the person’ as an individual includes respectful commu- nication, promotion of privacy and of autonomy, and of a sense of control. It requires the sensitive addressing of basic needs such as nutrition, elimination, and personal hygiene, and the promo- tion of inclusivity and participation by providing information and enhancing communication to support decision-making, with recognition that even in the presence of some impairment of cognition, the wishes and views of the patient remain central to decision-making. Elder abuse Elder abuse was first described in 1975, and general clinical aware- ness of this problem has grown since that time. Although the early research was derived from populations in the Western world, data from around the globe has indicated that it is a worldwide problem. The most widely used definition of elder abuse comes from the World Health Organization: ‘A single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.’ The person in a relationship of trust with the older person may be a family member, friend, or neighbour, or a paid (‘formal’) care- giver, including both health and social care workers. Types of elder abuse include as follows: • Physical abuse including acts done with the intention causing physical pain or injury. These may include assault, hitting, slap- ping, pushing, burning or scalding, misuse of medication, and restraint. • Psychological abuse, defined as acts done with the intention of causing emotional pain, including emotional abuse, threats of harm or abandonment, deprivation of contact, humiliation, blaming, controlling, intimidation, coercion, harassment, verbal abuse, isolation, or unreasonable withdrawal of services or sup- port networks. • Sexual assault, including rape, indecent exposure, sexual harassment, inappropriate looking or touching, sexual teasing or innuendo, sexual photography, subjection to pornography or witnessing sexual acts, indecent exposure or sexual assault, or sexual acts to which the person has not consented or was pressured into consenting. • Financial abuse, including misappropriation of the older person’s money or property, including theft, fraud, coercion in relation to a person’s financial affairs or arrangements including in connec- tion with wills, property, inheritance, or financial transactions (e.g. loans) or the misuse or misappropriation of property, pos- sessions, or benefits. • Neglect, or the failure of a designated carer to meet the needs of the dependent older person, including ignoring medical, emo- tional, or physical care needs, failure to provide access to appro- priate healthcare and support, the withholding of the necessities of life such as medication, adequate nutrition, and heating. Estimates of the prevalence of elder abuse have been difficult as definitions used in the past have varied, and as surveys tend to under-report due to the tendency of abuse to be hidden. A further Box 6.11.5 Challenges to provision of dignified care by hospital staff • The view that an acute hospital is not the right place for older people • Attention paid to those factors on which a hospital’s success is seen to rest, which may have unintended consequences on dignity in care • ‘Seeing the person’: person-centred, not task-driven care

6.11 Promotion of dignity in the life and death of older patients 615 confounding factor is the higher rate of abuse among those with dementia or depression; both of these populations are less likely to be able to respond to surveys. Not all studies have used the same definition of abuse. With these caveats, the rates reported are shown in Table 6.11.1. While the precise prevalence of various forms of abuse is un- certain, the phenomenon occurs sufficiently frequently that all clinicians who come into contact with older people are likely to en- counter it in their routine practice. It is noteworthy that the preva- lence of abuse identified in surveys far exceeds that reported to adult protection services, indicating that the vast majority of abuse goes unreported, using statutory procedures. Abuse of older people can occur in several environments; within their own home, a care home, or an acute hospital setting. The term ‘institutional abuse’ has been used to describe abuse that is the re- sult of organizational action or inaction, for example, as the result of inappropriate policies, poor staff training, and education. So risk factors arise across several domains (Box 6.11.6). Evidence on the role of physical (rather than mental) infirmity as a risk factor for receiving abuse is conflicting. Older people who suffer one form of abuse may be subject to other forms: for ex- ample, those subject to physical abuse are likely also to be abused financially. In some cases the pattern of elder abuse is a continu- ation of an abusive relationship that antedates old age. Cases also occur when a previously abusive male partner is abused by his female partner when he is old, frail, and no longer the dominant partner. Cultural differences may influence perception of what consti- tutes abuse: for example, the use of physical restraints is regarded as acceptable in some healthcare systems and regarded as unaccept- able in others; in some cultures there is an expectation that family members may act as a proxy for the views of the older person, re- gardless of their capacity to make decisions, whereas others would regard this as an abuse of autonomy. Identification of abuse Doctors, nurses, and other medical personnel can play a vital role in assisting elder abuse victims. Studies have shown that elderly individuals, on average, make 14 visits per year to a primary or secondary care physician, and therefore opportunities for earlier recognition of abuse may be currently unidentified. Although there has been an increase in awareness of elder abuse over the years, physicians tend to only report 2% of elder abuse cases. Reasons for lack of reporting by physicians include a failure to recognize signs of abuse, lack of current knowledge concerning laws on elder abuse, concern about the possible reaction of the abuser, and the impact on the relationship with the older pa- tient. Other concerns include anxiety about possible court ap- pearances, actual or anticipated lack of cooperation from elderly patients or families, and a perception of lack of time or reim- bursement for time. Education is clearly important to equip clinicians to identify the signs of possible abuse. A European undergraduate curriculum for geriatric medicine, devised using a modified Delphi technique (with agreement between representatives of 29 countries) includes elder abuse. However, a survey of UK medical schools indicated that this topic was not taught in 35% of schools, and it was exam- ined in only 29%. Clinical assessment of the person at risk of abuse There are no validated screening tools recommended for routine use to detect elder abuse. Clinicians are required to be aware of risk factors and alert to indications of possible abuse. Although abuse can occur in situations with none of the risk factors listed in Box 6.11.6, the presence of one or more risk factors should heighten awareness. There are few specific diagnostic signs, as bruising, fractures, la- cerations, burns, and head injuries can happen either as a conse- quence of falls or accidental injury or of abuse. These may be noted in an initial assessment while beginning to take the history and establish rapport. Weight loss is common in those with frailty as well as in neglect. Medication nonadherence may be an innocent misunderstanding or intentional over- or undertreatment. Although the issues in history and examination are listed sep- arately in Box 6.11.7, in practice the overall picture is built

grad- ually, in an iterative manner, reacting to observations made. This may not be completed at one session, but if a patient is thought Table 6.11.1 Prevalence of reported abuse by type Type of abuse Percentage Abuse (all forms) within the preceding month (community dwelling elderly people) 6% Physical abuse within the previous year (within their relationship, elderly couples) 6% Significant psychological abuse within the previous year (disabled older adults) 25% Family carers reporting physical abuse towards care recipients with dementia within the previous year 5% Care home staff admitting perpetrating significant psychological abuse 16% Rates of abuse reported to adult protection services 1–2% Box 6.11.6 Risk factors for abuse • Living with others (rather than alone), with increased risk of conflict and friction. This applies for all forms of abuse except financial, which is commoner in those living alone. • Dementia: people with dementia are at higher risk of abuse. The mechanism is thought to be through the increased stress found among carers of dementia patients. Sleep disturbance or behavioural disturbance (especially if aggression or violence occurs) may be a trigger. • Social isolation: the victim is more likely to be isolated from friends and family (apart from their caregiver) than nonvictims. Isolation can lead to an increase in stress in the caregiver and abusive behav- iours can be hidden in the absence of others who might otherwise intervene. • Mental illness (especially depression) in the caregiver is more common than in nonabusing caregivers. Alcohol abuse in the abuser is also associated with an increased risk of abuse. • Financial reliance of some caregivers on the dependent person is another factor more commonly seen in abusers. This may prevent a care-giving son or daughter from leaving home, or may result in attempts by the caregiver to extract money from the victim.

616 Section 6 Old age medicine to be at ongoing risk, then early action may be necessary. A team approach is vital. A thorough assessment with investigation as to the cause of any abnormalities identified is required. Victims will commonly be ashamed that they have been abused and a sensitive approach is essential. If abuse seems likely, then the history should include the nature, frequency, severity, and context of the abuse. Responding to definite or suspected abuse This will depend on the situation (Box 6.11.8). Immediate treat- ment to injuries is a priority, though it may be appropriate to obtain photographic evidence. Where a criminal offence is suspected, then forensic evidence collection is a priority. If a criminal offence has been committed or is suspected, the police should be informed. Actions which may constitute crim- inal offences are assault (physical or psychological), sexual assault and rape, theft, fraud, or other forms of financial exploitation, and some forms of discrimination such as on the grounds of race or gender. In cases of alleged criminal offences the responsibility for initiating prosecution is with the state (the police force or public prosecution service). Agencies such as health, social care, and police services need to work together to ensure a properly coordinated joint investigation takes place, minimizing distress that results from repeated interviewing. The older person’s emotional, physical, intellectual, and mental capacity in relation to self determination and consent, and any intimidation, misuse of authority, or undue influence, must be as- sessed. Assessment of ‘capacity’ with regard to decision-making about abuse is the key to action. Careful assessment is required if an older person chooses to make decisions which place them at risk of being abused or neglected. People are assumed to have capacity to make their own decisions. Barriers to decision-making (e.g. sensory deficits or communication difficulties) must be addressed to maximize the opportunity of the elder to participate fully in decisions about their care. If someone has capacity and declines assistance, this limits the help that he or she may be given, but action may be required to protect others who are at risk of harm. Outcome for victims of abuse Victims of abuse are more likely to experience adverse outcomes compared with nonabused elders with a similar burden of

comorbidities. They are more likely to die, to be admitted to a care home, and to suffer from depression than their peers. Admission to hospital is commoner in those whose abuse has been reported to adult protection services, compared with others with similar burden of comorbidities but not subject to abuse. Prevention of recurrent abuse A carer who experiences unintentional or intentional harm from the adult they are supporting, or a carer who unintentionally harms or neglects the adult for whom they are caring, may need a careful assessment to establish whether the risk of future abuse can be mitigated by provision of treatment, training, or support. An understanding of the factors that led to abuse may allow a remedial course of action. This might include additional support if carer strain is implicated, support for abstention from alcohol, treatment of depression, or support and treatment in managing ag- gression in patients with dementia. Dignity at the end of life Recognition of the patient reaching the end of life In economically developed countries, increasingly ageing popu lations mean that more people are dying over the age of 85, hence Box 6.11.7 Clinical assessment History • Anticipate: being aware of risk factors and heightened attention to signs which may suggest abuse or neglect • Seek to establish trust and speak in private with the subject • Notice if the carer seems reluctant to facilitate or ‘allow’ this privacy (as the carer may be the abuser) • Enquire directly about any episodes of abuse (physical, emotional, sexual (if indications that this may have occurred) or financial), but using simple words and questions (e.g. ‘do you feel afraid or anxious when you are being helped … is there anything happening to you at home that you wish was different?’) • Elicit explanation from a carer (possible abuser) for any suspicious findings or allegations, but do this sensitively and avoid ‘acting the policeman’ • If any other informants are available elicit their observations Examination • Note signs of psychological distress • Note general state of hygiene and cleanliness • Examine for signs of dehydration • Note any skin lesions (bruises, lacerations, and so on) and any pressure injury • Note any evidence of traumatic alopecia, and bruises or welts, espe- cially if in an unusual shape or pattern • Rectal or vaginal bleeding or evidence of sexually transmitted infection • Trauma to the wrists or ankles may indicate the use of physical re- straints; glove or stocking distribution scalding may indicate immer- sion burns. Identify symptoms or signs of depression and evidence of dementia (using a formal cognitive test) Box 6.11.8 What happens when an allegation of abuse has been made? • investigation of the complaint • assessment and care planning for the vulnerable person who has been abused • consideration of criminal proceedings • action by employers, such as suspension, disciplinary proceedings, use of complaints and grievance procedures, and action to remove the perpetrator from the professional register • arrangements for treatment or care of the abuser if appropriate, con- sideration of the implications relating to regulation, inspection, and contract monitoring

6.11 Promotion of dignity in the life and death of older patients 617 patterns of disease at the end of life are changing. The World Health Organization considers palliative care for older people to be an ur- gent public health priority. In countries where palliative care is better established, the focus has been on cancer. But in these countries, older people are now more likely to die with multiple comorbidities, including frailty and dementia, in which palliative care needs are less easily defined. The summative effect may be much greater than might be expected from the individual components, with resultant complexity of presentation and need. Thus recognition of the ter- minal phase of illness can be particularly challenging. Recognizing when people enter the last year of their life is im- portant to achieve the right focus of care for older people. While most people will opt for the offer of investigation and disease- orientated treatments where potential for recovery is reasonable, it is the healthcare professional’s role to identify those clinical situ- ations where the

patient would likely benefit from a change in the goal of their treatment to supportive and palliative care. This recognition facilitates communication with patients and families and enables the implementation of anticipatory care plan- ning. It allows assessment of future needs and appropriate align- ment of care with patient wishes. For those patients who would prefer to avoid futile and aggressive interventions, which might be burdensome, and include hospital admissions, forward planning allows prioritization of appropriate care in the patient's preferred place. Many people do not die at home, although most would wish to. In England, most deaths occur in an NHS hospital. Recognizing when people are approaching the end of their life is difficult, and healthcare professionals tend to err towards an op- timistic prognosis. Identifying those who are unlikely to survive more than 12 months is very often more difficult than identifying those who have reached the last days of life. These days, most people die when they are old, and older people are more likely than young to acquire a serious and disabling progressive illness that gradually interferes more with their daily activities until death. Individuals vary, but three trajectory patterns have been described (Box 6.11.9). Trajectory 3 is more common in older patients, particularly those aged over 85 with multimorbidity, dementia, and frailty. One-quarter of people over 85 have dementia. The end stages of dementia can last two or three years and there may be an absence of a terminal phase, or—because there is only slight acceleration of the trajectory of functional loss as death approaches—the point at which a patient enters this terminal phase may be very difficult to recognize. The coexistence of other factors may result in typ- ical late stage features, such as swallowing difficulties, appearing earlier. These patients on trajectory 3 may benefit from inclusion of a palliative approach to their care before they reach a terminal phase, although involvement of specialist palliative care is un- common, as it is also for patients on illness trajectory 2. The stra- tegic need for these groups is to incorporate the end-of-life care approaches and necessary palliative treatment skills in primary and community services and medical specialties such as geriatric medicine. It is very difficult to predict prognosis in frail older popula- tions. Disease specific prognostic tools are of limited usefulness because they are insufficiently accurate in predicting survival of patients with multimorbidity. Conversely, the rate of func- tional decline, measured as deteriorating performance status, is strongly correlated with prognosis in patients with advanced illness, regardless of diagnosis. Thus monitoring the patient over a period of time will provide an insight into the momentum of decline, and this is likely to provide the most accurate estimate of prognosis. This period of observation also allows for recogni- tion and treatment of reversible causes of deterioration. Broadly speaking, patients observed to have a monthly or weekly deterior- ation are likely to have a prognosis measured in months or weeks. Those who are deteriorating daily are likely to have a prognosis measured in days. In the United Kingdom, the National Gold Standards Framework uses general prognostic indicators of decline alongside clinical features specific to advanced single organ diseases, such as heart failure, to identify patients at the end of life. For those on illness tra- jectory 3 with multimorbidity, general prognostic indicators may be more useful (Box 6.11.10). For those patients identified as reaching end of life, it is im- portant to recognize their transition to the actively dying phase of their illness in order to facilitate a 'good death'. Diagnosing dying may be difficult when based on subjective assessment of clinical decline over time, particularly when done by individual professionals and therefore dependent on continuity of care. But signs and symptoms of impending death can often be rec- ognized and then should be communicated to the patient and their family. Remember that however much this seems like a natural pro- gression to the healthcare professional, the actuality of death may still come as a shock to both the patient and their family despite great age, frailty, and multiple comorbidities. It may be Box 6.11.9 Illness trajectories at the end of life Trajectory 1 is most commonly seen in

cancer and describes a short period of reasonably predictable, rapid decline over weeks or months. Where palliative care services exist, this is the group that has been well-catered for. Trajectory 2 is associated with organ failure, for example, chronic obstructive pulmonary disease or heart failure. Typically, these pa- tients experience long-term progressive limitations with intermittent periods of crisis often requiring hospitalization. Each crisis has the potential to result in death, but often does not, with the recovery being not easily predictable and often incomplete. Trajectory 3 describes an extended period often over a few years of ‘prolonged dwindling’ in which there is general deterioration on a background of poor baseline physical and/or cognitive function. This decline may be interjected by periods of ill-health requiring hospitalization (e.g. for pneumonia or fractured neck of femur, with resultant acute deterioration in baseline function). Box 6.11.10 General prognostic indicators of decline towards end of life 1 Deteriorating functional status. Limited self-care; in bed/chair more than 50% of the day 2 Progressive weight loss (more than 10%) in the last six months 3 Two or more unplanned admissions in the last six months, or sentinel event (serious fall, bereavement, transfer to a nursing home) 4 Increasing care requirement or nursing home residency

 appropriate to give a trial of treatment (e.g. antibiotics) if it is thought that the cause of deterioration could be reversible and the diagnosis of dying is in doubt. This should be reviewed regularly, and further intervention should be stopped if there are ongoing signs of deterioration despite treatment. Communicating this ambiguity is important for the support of staff as well as for pa- tients and families. In the last days of life, patients may become increasingly drowsy with an acute deterioration in functional status, becoming bed bound and semi-comatose as death approaches. Interest in food/ fluids diminishes; there may be increasing difficulties with swal- lowing and consequently taking oral medication is compromised. Poor cardiac output may result in mottled skin, cold peripheries, and reduced urine output. Poor cerebral perfusion may precipi- tate a terminal delirium with agitation or restlessness. With a re- duced level of consciousness, the patient may be unable to clear upper airway secretions and develop noisy gurgling respirations. Towards the last few hours of life, Cheyne–Stokes respirations with apnoeic episodes may occur. A diagnosis of dying should prompt a timely, frank discus- sion with family members and an explanation of the transition of the goals of care from ‘cure’ to ‘maintaining comfort’. It is important that all the healthcare staff involved understand that the patient is dying and focus their goals of care appropriately in order to facilitate well-coordinated end-of-life care that meets the patient’s physical, psychosocial, and spiritual needs. This should be considered a positive change to achieve ‘dignity in death’. A medication review should be undertaken, stopping those that do not provide symptomatic benefit and prescribing ‘as required’ medications for symptom relief. For example, mor- phine may be prescribed for pain or breathlessness and mouth care administered to prevent discomfort from a sore mouth (see Chapter 6.7). Anticipatory care planning In patients who are identified as nearing end of life, anticipa- tory care planning is key to ensuring that they live and die in the manner that they wish. Care at the end of life is often provided by multidisciplinary teams from health and social care and the vol- untary sector. Planning ahead enables optimum coordination to facilitate timely adaptations of care to meet the changing needs of the patient. Anticipatory care planning is the process of decision-making with regards to future care that can come into effect when the patient no longer has capacity. It is not unusual for very sick elderly patients to present when they no longer have capacity and without any formal advance care plans. However, it may be possible to plan for care in potential future situations (e.g. ad- missions to hospital), guided by best interests and discussions with family,

taking into account the patient's previous beliefs and behaviours. An advance care plan must be freely made without coercion while the individual still has mental capacity. It cannot be used to request a specific medical intervention or refuse basic care such as food or water by mouth. In the United Kingdom, antici- patory care planning takes on three main forms as described in Box 6.11.11: although things may differ slightly elsewhere, the basic principles apply. An advance decision to refuse treatment may be invalid if the patient had withdrawn their refusal while they still had capacity, or the patient has behaved in a way that was inconsistent with the de- cision while suggesting that they might have changed their mind. Alternatively, it would be invalid if the patient had subsequently appointed a surrogate decision maker and given them authority to make decisions with regards to the treatments covered in the ad- vance decision. An advance decision to refuse treatment would not be applic- able if the proposed treatment and/or the circumstances differ to that specified, or if the circumstances have changed such that there are reasonable grounds to believe that this would have af- fected their decision had they known about it while they still had capacity; for example, if a new disease-modifying treatment has become available. In the event of an advance decision to refuse treatment being invalid or not applicable, a best interests deci- sion should be made with consideration to the wishes set out within it. Anticipatory care planning empowers patients to have input into their current and future care. It allows respect for patient au- tonomy and preparation for the possibility of loss of capacity in the future. There is evidence that it results in less aggressive med- ical care and fewer hospital admissions. In patients who are re- ceiving hospice care in the United Kingdom, 10% of patients who have undertaken anticipatory care planning die in hospital, com- pared to 25% of those patients who have not. The ability of family Box 6.11.11 The three main forms of anticipatory care planning 1 Advance statements. These are documented statements of pref- erences, wishes, beliefs, and values regarding future care. They may relate to medical treatments and/or nonmedical aspects of care. An advance statement is not legally binding, but should be used when the patient no longer has capacity to guide management when a best interests decision is being made. 2 Advance decision to refuse treatment (ADRT). This is a legally binding document in which a patient states a clear refusal of a particular treatment if they no longer have capacity in the future. It is preferable, but not required, that the patient gives specific cir- cumstances in which they would refuse the specific treatment because this will reduce ambiguity and guide clinicians in whether an ADRT is valid and applicable. An ADRT for life-sustaining treat- ment should be signed and witnessed, and if valid then should be adhered to. 3 Lasting power of attorney (LPA). This allows patients to nominate a person (attorney) who they want to act as a surrogate decision- maker should they lack capacity in the future. In the United Kingdom, these are divided into two types; 'property and financial affairs' and 'health and welfare'. If there are concerns that the attorney is not making decisions in the patient's best interests, then their decisions can be challenged.

 members to cope with bereavement is directly influenced by how prepared they are for the death of their relative and anticipatory care planning can reduce the incidence of anxiety, depression, and post-traumatic stress in surviving relatives. FURTHER READING Boland B, Burnage J, Chowhan H (2013). Safeguarding adults at risk of harm. BMJ, 346, f2716. Boyd K, Murray SA (2010). Recognising and managing key transi- tions in end of life care. BMJ, 314, c4863. British Medical Association (2011). Safeguarding vulnerable adults—
a tool kit for general practitioners. BMA. http://bma. org.uk/-/
media/Files/PDFs/Practical%20advice%20at%20work/Ethics/ safeguarding vulnerableadults.pdf

Christakis NA, Lamont EB (2000). Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. BMJ, 320, 469–72. Coventry PA, et al. (2005). Prediction of appropriate timing of pal- liative care for older adults with non-malignant life-threatening disease: a systematic review. Age Aging, 34, 218–27. Department of Health (2008). End of life care strategy: promoting high quality care for all adults at the end of life. Department of Health, London. Kennedy C, et al. (2014). Diagnosing dying: an integrative literature review. BMJ Support Palliat Care, 4, 263–70. Lau F, et al. (2009). Using the palliative performance scale to provide meaningful survival estimates. J Pain Symptom Manage, 38, 134–44. Lynn J, Adamson DM (2003). Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age. RAND Corporation, Santa Monica, CA. https://www.rand.org/pubs/white_papers/ WP137.html Mullick A, Martin J, Sallnow L (2013). An introduction to advance care planning in practice. BMJ, 347, f6064. Murray SA, et al. (2005). Illness trajectories and palliative care. BMJ, 330, 10071011. National Audit Office (2008). End of life care. National Audit Office, London. National Gold Standards Framework Centre England (2008). Prognostic Indicator Guidance Paper 2008. https://www.goldstandardsframework.org.uk Royal College of Physicians (2009). Advance Care Planning: Concise Evidence-based Guidelines. https://www.rcplondon.ac.uk/guidelines- policy/advance-care-planning Tad W, Bayer T, Dieppe P (2002). Dignity in health care: Reality or rhetoric. Reviews in Clinical Gerontology, 12(1), 1–4. Woolhead G, Calnan M, Dieppe P, Tadd W (2004). Dignity in older age: what do older people in the United Kingdom think?, Age and Ageing, 33(2), 165–70. World Health Organization (WHO) (2011). Palliative care for older people: better practices. World Health Organization, Geneva, Switzerland.

Revision #1
Created 2026-01-22 16:44:34 UTC by Omar Ayman
Updated 2026-01-22 16:44:34 UTC by Omar Ayman