End-of-Life Symptoms

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Abstract
Safe care at the end of life involves much more than just prescribing for end-of-life symptoms. An approach of whole person care is one in which respect for the individuality of the dying person is fundamental, and this can sometimes present real challenges for clinicians. Diagnosis of dying is a key clinical skill, and the use of triggers can assist clinicians to recognize patients who are likely to enter the terminal phase soon. Early recognition creates the opportunity to plan care and to share decision-making about goals of care with patients, allowing more choices about how and where the dying person may wish to be cared for. Common symptoms at the end of life include pain, nausea, respiratory secretions, dyspnea, agitation, and delirium. Prescribing for the end of life involves, on the one hand,
ceasing unnecessary medications and interventions and, on the other, providing and using comfort medications appropriately and effectively. Psychosocial care of the dying person focuses on their personal and spiritual needs at the end of life. Decision-making about what interventions are appropriate at the end of life is based on weighing up the likely benefit versus the burden of such interventions, assessing this in the context of the patient’s prognosis. Decision-making at every stage must include the dying person as much as they are able and wish to, as well as their family and close supporters. It is therefore essential that clinicians are able to communicate comfortably and empathically about end-of-life concerns.

1 Introduction

So come, my friends, be not afraid. We are so lightly here.
It is in love that we are made. In love we disappear. Though all the maps of blood and flesh are posted on the door,
There’s no-one who has told us yet what Boogie Street is for.


Care for dying people at the end of life is a core role of palliative care. It is also a responsibility that is shared with every domain of medicine, and as such it is “everyone’s business.” The palliative care approach acknowledges that death is a normal, inevitable, mysterious, and natural phenomenon in which the focus of care should be to comfort and support. Palliative care practitioners have played a very significant part in putting the care of dying people onto the health-care agenda as a domain requiring evidence, skills, and appropriate models of care. Being able to die a natural death with distressing symptoms treated, to have choices wherever possible about where death occurs and who is present, and to be given culturally appropriate care that supports one’s individuality and dignity and is responsive to psychological and spiritual needs – these are appropriate outcomes for end-of-life care and are indicators of quality care for the dying. An example of a statement of the principles associated with safe dying (Box 1) is contained in the Australian Commission on Safety and Quality in Health Care National Consensus Statement (ACSQHC 2015).


1. Dying is a normal part of life and a human experience, not just a biological or medical event.
2. Patients must be empowered to direct their own care, whenever possible. A patient’s needs, goals and wishes at the end of life may change over time.
3. Providing for the cultural, spiritual and psychosocial needs of patients, and their families and carers is as important as meeting their physical needs.
4. Recognising when a patient is approaching the end of their life is essential to delivering appropriate, compassionate and timely end-of-life care.
5. The prognosis and the way that people respond to medical treatment will vary between individuals. This means that there is potential for ambiguity and uncertainty at the end of life. This must be honestly and openly acknowledged, and discussed with patients, substitute decision-makers, families and carers.
6. Safe and high-quality end-of-life care is patient and family-centred. Whenever possible, it should be aligned with the values, needs and wishes of the individual, and their family or carers. Such care should consider the patient’s expressed wishes regarding the (continued)
Box 1 (continued)
circumstances, environment and place in which they wish to die.
7. Safe and high-quality end-of-life care requires the availability of appropriately qualified, skilled and experienced interdisciplinary teams.
8. Safe and high-quality end-of-life care requires effective communication, collaboration and teamwork to ensure continuity and coordination between teams, within and between settings, and across multiple episodes of care.
9. Care of the dying is urgent care. Timely recognition of a patient’s transition to the terminal phase of life must be documented and communicated to patients, families, carers and other health professionals by the interdisciplinary team. The care plan must be specifically revised to meet the unique needs of the patient, family and carers during this phase.
10. End-of-life decision-making should be shared between the interdisciplinary team and the patient. Substitute decision-makers, families and carers should be involved, in accordance with the patient’s expressed wishes and/or jurisdictional legislation.

Nonetheless, in developed countries many people die in hospitals while receiving care that is burdensome and non-beneficial, with continuing investigation, monitoring and treatment, and lack of good symptom management, and the goals of care do not shift toward comfort and palliation of symptoms until quite close to the patient’s death (O’Brien et al. 2006; Wright et al. 2014; West et al. 2014; Swerrisen and Duckett 2014; Henson et al. 2016). Other settings of care (home, residential aged care facility) may allow an experience of death which is less interventional, but these present different challenges in order to ensure that care and symptom management are adequate and responsive to the patient’s and family’s needs. This chapter will discuss care of dying people and explore the practical implementation of principles of safe end-of-life care.

2 Whole Person Care: The Dying Person and Their World

The aim of palliative care for dying patients is to promote their comfort and dignity. However, it is important for clinicians to be aware that what is meant by comfort and dignity may be very different for different people. Their life experiences; their networks of relationships; their values and beliefs; their strategies for coping; the experience of and meaning given to their symptoms, illness, and death; their perception of death as a tragedy, as meaningless, or as the completion of life; and the story of how their illness has brought them to be dying at this particular time and place—all of these things go into the individual’s own construction of what is meant by comfort and dignity. This is what clinicians must try to respond to.

Clinicians who work in palliative care inevitably become very familiar with the appearances and symptomatology of dying people. This very familiarity, however, may dull them to the mystery of this once-only process for the dying person her- or himself and for all those who care about them. Clinicians need to be able to treat each person as an individual, but meeting the very individual wishes and needs of dying people may require considerable creativity and flexibility. Sometimes this is in tension with other goals of providing good palliative care, with their focus on the provision of evidence-based care and protocol-based care planning. Negotiating processes of care with the dying person and their network of supporters requires some space to be left within protocols, guidelines, and pathways to enable clinicians to individualize their responses. This is a very fundamental tension within palliative care and particularly in inpatient settings may sometimes create ethical, clinical, and human dilemmas.

When clinicians care for patients, a degree of medicalization is inevitable. Assessment and care processes allow us to define and manage problems
within a clinical framework, but this can sometimes be experienced as an intrusion within the world of the dying person. Even when patients are cared for in their own home, this medicalizing process still occurs, changing the home environment into something more institutional, intruding on people’s privacy, and taking some of the decisions about how to care for the dying person away from family and friends, putting them instead in the hands of clinicians. Great gulfs of mutual misunderstanding can sometimes arise from differences in culture or when caring for those in stigmatized or socially marginalized groups. Difficulties in relating to health-care providers which may have been present throughout the illness trajectory will often intensify at the end of life. Care for dying people ultimately requires great trust from them and from their friends and families, and this trust is needed most at the time when distress and care needs are peaking. Some dying people and their supporters may struggle with conflicting concerns – their intensifying needs for help, care, and information on the one hand, versus distress at being caught within a healthcare system that is experienced as intrusive or threatening on the other (Luckett et al. 2011; Hanssen and Pedersen 2013; Francois et al. 2017).

In the intimate space of the dying person’s world, clinicians have to be mindful of how their own anxieties and judgements, and the language in which these are expressed, can make people feel more or less safe and accepted. A whole person care approach requires acknowledgment of different worldviews – views that may potentially be very challenging during the intensity of the final days and hours of life, which is a time when these things matter very much to people. There may not always be a way to resolve the resulting tensions; however, care is able to be more authentic and honest if any differences are acknowledged and respected. That in itself helps to build trust. Individual and team clinical processes such as case reviews, mentoring, and debriefing are important in creating a culture of whole person care and may help clinicians to meet each dying person as a person with a new story, afresh, and still thrive while doing this work.

3 Planning for Expected Death

For most palliative care patients, death can be regarded as expected, based on the nature of their condition and the lack of curative treatment options available for them. Expectedness creates the opportunity for planning and choices about care and treatment and for dying people to focus on their own priorities in the last period of their life. However, this opportunity is largely dependent on clinicians being willing to talk clearly about prognosis, being comfortable to discuss dying with patients and their families in a timely way, and being aware of the options that are available in their own community to allow choices for people who are dying, such as referral to palliative care services (Clayton et al. 2007). Many patients and families are still shocked and unprepared for the dying process, even when this is thought by clinicians to be expected (Sanderson et al. 2013; Kehl 2015; Ek et al. 2015; Lamden et al. 2016).

For those people who would prefer to die at home, careful planning for an expected death is needed to ensure that end-of-life symptoms are able to be treated appropriately. Strategies such as the Gold Standards Framework (http://www.goldstandardsframework.org.uk/home) provide a model of care that can guide provision of end-of-life care in a primary care setting. Preemptive prescribing for end-of-life symptoms is important to allow prompt initiation of treatment in the event of a sudden deterioration, and this involves ensuring that there is ready, safe access to needed comfort medications, which is especially critical when a home death is planned (NICE 2015). Documenting an advance care plan to ensure that transitions of care (between home and hospital, or between different settings of care) can be made safely if required is another essential element in planning for an expected death. Such documentation is needed to protect dying people from unwanted and burdensome interventions such as cardiopulmonary resuscitation. Preparation of family carers to look after a dying person at home is also essential, and ongoing support and access to advice will be needed.
4 Diagnosing Dying

In order to be able to provide appropriate care and to cease treatments that are no longer beneficial, it is essential to be able to diagnose dying – yet it is not always easy to identify the point at which a patient who is approaching death makes the transition to being a dying patient (Haga et al. 2012).

Symptoms associated with the onset of the terminal phase have been identified in a number of studies. A systematic review identified the most common symptoms found in patients who are dying as dyspnea (56.7%), pain (52.4%), respiratory secretions/death rattle (51.4%), and confusion (50.1%) (Kehl and Kowalkowski 2013). Functional changes, particularly the inability to swallow, reduced oral intake, reduced level of consciousness, and becoming bedbound, have traditionally been used as criteria to identify dying patients in end-of-life care pathways, but these have not been prospectively validated in robust studies (Chan and Webster 2011; Phillips et al. 2011; Watts 2012). However, a large cohort study based on the use of standardized assessment tools for symptom burden and functional state confirmed that at the time of entering the terminal phase, more than 90% of patients were bedbound and 50% were either comatose or barely rousable. The majority (73.6%) of the patients who were identified as being in the terminal phase in this study survived no longer than 2 days, 23.2% of them dying on the same day that they were assessed as being in the terminal phase (Clark et al. 2016).

The terminal phase therefore presents with a fairly recognizable syndrome, and in acute care settings, the onset of the terminal phase is very often the main trigger for ceasing active treatments and for changing goals of care (Cardona-Morrell et al. 2016). However, given the features of this syndrome, the associated alterations in the level of consciousness, and how rapidly it may progress to death, it is important to understand that the onset of the terminal phase is far too late for many of the social, spiritual, and relational tasks that are important to dying people (Steinhauser et al. 2000, 2014; Virdun et al. 2015). In particular, for families who may wish to care for their dying family member at home, earlier planning and decision-making is absolutely essential. The diagnosis of dying is a clinical assessment, and it is important that this should be a positive diagnosis made in a timely way, rather than happening at the last hour. No single diagnostic tool or measure has been identified that can support clinicians in identifying the dying patient, particularly across different diagnostic groups and in varied settings. One evolving strategy is the use of “trigger tools” or identification of sentinel events that can prompt clinicians to consider whether a patient may be at risk of dying soon (Hussain et al. 2014) and if so to reassess their goals of care accordingly (Box 2). This allows preemptive prescribing for end-of-life symptoms and encourages earlier discussions with the patient and their family, so that they can participate in decision-making and make informed choices about their wishes for treatment and care.

**Box 2 Triggers and Sentinel Events Indicating Patient Is Approaching End of Life (Adapted from ACSQHC 2015)**

- Diagnosis of life-limiting conditions
- Poor or incomplete response to medical treatment, continued deterioration despite medical treatment, and/or development of new clinical problems during inpatient admission
- Repeated calls to the rapid response team, particularly if the patient has been admitted for more than 1 week
- Advanced age with increased frailty, reduced mobility and increased dependence on others to assist in performing activities of daily living
- Moderate to severe dementia
- Multisystem comorbidities (cardiovascular, pulmonary, endocrine, etc.)
- Maximal medical therapies already in place
- Decline in the patient’s condition, or a clinical determination that they will not

(continued)
Deciding that a patient is at risk of dying soon requires an assessment of the person’s overall condition, illness trajectory, performance state and level of functioning, their past responses to treatment and the likely outcome of treatment now, and their wishes. Understanding when a patient’s problems are no longer likely to be reversible, or when multiple problems have additively overwhelmed a person’s ability to recover, is an important clinical skill which is rarely formally taught. Factors that impede the identification of the dying patient have been studied (Kennedy et al. 2014), and many relate to the “treatment orientation” of health-care providers. The presence of clinical uncertainty often leads health-care providers to default to continuing active management while neglecting the dying person’s comfort and their human needs. The process of assessing the potential reversibility of a patient’s problems may in itself lead to a cascade of burdensome treatments and investigations, particularly if a holistic assessment of the patient’s overall condition and wishes has not been made. The clinical cascade in response to uncertainty often results in postponing important conversations and decisions until very late – indeed these may not happen until the patient themselves can no longer participate. Even when a situation is clinically challenging, particularly when there is a degree of clinical uncertainty, sharing decision-making processes with the patient and their family can sometimes provide a path through the available options. If it is possible to have a conversation focusing on what is important to the person now, in the context of having a short time to live, that can be extremely helpful in coming to agreement about goals of care and the tradeoffs that may be involved in different options.

5 Symptoms at the End of Life

5.1 Fundamentals of Physical Care

As death approaches, it becomes ever more important to actively and regularly assess all aspects of a dying person’s physical comfort and to prescribe preemptively for the common symptoms that can be expected. Assessment of a person who is not able to respond verbally requires careful observation for signs of discomfort or pain and regular focused examination related to comfort. Frequent attention to skin and mouth care, to the eyes (e.g., by providing lubricating eye drops), to the sleeping patterns, and to the person’s mental state (whether the person is aware and able to communicate, whether they appear relaxed or distressed or fearful, whether there is any evidence of hallucinations) is part of the routine of caring for patients entering the terminal phase.

Supporting bladder and bowel function should be individualized according to the person’s physical needs and functional state and are essential for comfort. For many patients, the capacity to toilet themselves independently is a fundamental component of dignity, and so any intervention needs to be offered with sensitivity. Unidentified urinary retention or fecal impaction is a significant cause of distress in dying patients and should always be checked for when a dying patient is restless and agitated. In-dwelling catheters have a place – they may be required if there is urinary retention, to protect the skin of an incontinent patient, or to prevent unnecessary moves for a patient in significant pain or other distress. However, a person with minimal urinary output and none of these problems may not necessarily require a catheter. Management for the bowels changes as patients...
approach death. Once they are no longer able to take oral aperients, gentle and judicious rectal intervention may sometimes be needed for comfort.

The most common symptoms that need to be looked for and addressed at the end of life are pain, nausea, respiratory secretions and respiratory distress, and delirium/agitation (NICE 2015; Blinderman et al. 2015). When a person is able to communicate, it is important to check with them about these and any other symptoms regularly. When a person is unable to communicate, the assessment is based on behaviors, for example, wincing, vocalizing, or stiffening when moved. Other assessments that are important relate to adverse effects of medications and treatments, for example, the presence of frequent myoclonic jerks, particularly associated with confusion, suggests opioid metabolite accumulation, while worsening edema while fluids are being administered suggests a need to cease parenteral fluids.

**Pain** is a feared problem and all dying patients require access to pain medications. Being bedbound, unable to move independently, and cachexic will produce a level of discomfort in many people even if there are no specific sites of pain. As needed opioids are the most appropriate choice to deal with this and should generally be given prior to turning the person or doing other personal care. Those previously on regular pain medications should have these continued in a parenteral form to maintain pain control and prevent withdrawal, possibly with some dose reduction to adjust for the changed metabolic parameters of the dying process, but with rapid access to as needed doses for any episodes of extra pain. Regular review of pain medication use and adjustment of doses are essential. Good explanations for families are also incredibly important, as the use of opioids in dying patients can be misinterpreted. Each breakthrough dose of any medication should be explained to the family, if they are present, and families should be encouraged to help assess the person’s symptoms and response to medications if they are able to do so (NICE 2015).

**Nausea** is often not easy to identify in a patient who is not alert. Reduced oral intake, including reduction in the number of oral medications, may reduce nausea for some patients. However, patients for whom nausea has been an ongoing problem, or who have a partial or complete bowel obstruction, should have regular parenteral antiemetics continued. When rationalizing a patient’s medications at the end of life, it is helpful to be aware that a range of medications may have antiemetic properties via different mechanisms, for instance, dexamethasone, antipsychotics, and antihistamines are all reasonably effective against some types of nausea. Patients on some or all of these agents may not require an additional regular antiemetic. All patients should, however, have an as needed antiemetic available, and wherever possible this should be selected on the basis that it is an agent which has been previously effective (Glare et al. 2011).

**Respiratory secretions** occur commonly in dying patients, usually in association with reduced level of consciousness and consequent loss of the normal ability to manage upper respiratory tract secretions. However, lower respiratory tract secretions secondary to edema or infection may also contribute. In general, it is thought that this problem is not distressing for patients, as it occurs most often when people are minimally conscious; however, some families may find these secretions (often called “death rattles”) very disturbing indeed. There is little evidence to support the use of antisecretory medications (Wee and Hillier 2008), and the preferred treatment involves frequent repositioning. Many medications used traditionally are strongly anticholinergic (e.g., atropine or hyoscine hydrobromide) and have a side effect profile that is associated with adverse effects in patients who are aware, such as dry mouth, urinary retention, and delirium. If antisecretory agents are used, they should be trialled soon after symptoms are noticed, and agents that do not enter the central nervous system are preferred (hyoscine butyl bromide, or glycopyrrolate).

Gentle suction may be appropriate if secretions are copious and visible, if the patient tolerates this. Discussion with the family is an essential part of
care in relation to this problem (Wee et al. 2006) as some people will be left with distressing and traumatic memories of the person’s death that are connected to this symptom. 

Respiratory distress may be suggested by increased respiratory rate and/or visible effort of breathing. Abnormal respiratory patterns such as Cheyne-Stokes or Kussmaul’s respirations are caused by significant dysregulation of normal breathing physiology, and families should be counselled to expect these changes. If there is any suggestion of increased respiratory drive or air hunger, opioids can be titrated to reduce the respiratory rate. The goal of oxygen therapy is comfort, not normalization of oximetry. It is not without adverse effects, such as pressure injuries from tubing or drying of mucous membranes. A patient who is dying of predominantly respiratory causes, such as upper airway obstruction or lymphangitis carcinomatosis, may sometimes require palliative sedation to relieve their respiratory distress. Any patient with risk of respiratory failure who is still aware and is afraid that they may die with severe breathlessness should be reassured that sedation can be offered to reduce their awareness, and this information will often be gratefully received. Sedation, when given, should be at an effective dose, taking into account prior medication exposure, and levels of sedation should be reviewed regularly and titrated to effect. Midazolam is often the initial agent of choice due to its rapidity of onset, and in a distressed patient commencement of an infusion of midazolam and an opioid (usually morphine, which has the strongest evidence for relief of dyspnea) should be accompanied by an appropriate loading dose so that sedation is achieved rapidly (Vargas-Bermudez et al. 2015; Barnes et al. 2016; Simon et al. 2016).

Agitation is often multifactorial. Sources of pain, distress, and discomfort should be looked for and treated. Possible causes such as severe hypoxia, seizures, or akathisia should be considered. However, agitated delirium is extremely common at the end of life, most likely due to the progressive biochemical and physiological changes associated with the dying process, and if it is due to these causes, reversal is not expected (Bush et al. 2014a). As such it should be managed as a refractory delirium. In the past this syndrome has been referred to as terminal restlessness, but this term is best avoided as it reduces the likelihood that a proper assessment of the symptom will be made. Often the picture is of a dying person who is confused and disoriented, and is struggling to get out of bed, throwing off bedclothes or needing to move continuously, and who will only settle for very short times. Another common presentation is that of a person with reduced awareness who is plucking at the bedclothes, or performing other repetitive motor activities, who may be hallucinating and calling out or vocalizing. For the imminently dying patient diagnosed with a refractory delirium, the goal of treatment is to provide enough sedation that they can be calm and safe. Sedation at an effective dose with antipsychotics and/or benzodiazepines, or with sedating antipsychotics such as levomepromazine, is appropriate to obtain that goal, and – as in all symptom management at this stage – the discussion of this plan with families is essential (Bush et al. 2014b).

5.2 Preemptive Prescribing and Crisis Medications

As needed medications should be charted for comfort, including as a minimum adequate doses for pain, nausea, and agitation or delirium. Preemptive prescribing of comfort medications that can be given parenterally, along with good documentation of when they should be given, is a hallmark of good end-of-life care (NICE 2015). They minimize the problem of distressing delays in getting symptoms under control if a dying patient deteriorates more quickly than anticipated. Providing regular background medications is also important to maintain good symptom control, especially for pain. Rationalization of medications and ensuring that comfort medications can be given by an alternative route, if a patient is not able to swallow, are important.

Most often in palliative care the subcutaneous route is used for medications (NICE 2015) because this is a minimally burdensome parenteral
route of delivery. Intramuscular and intravenous routes should generally be avoided due to the associated trauma for the patient. Subcutaneous lines can be maintained at home and have a low risk of infection. Syringe drivers can reduce the need for frequent bolus doses to be given and allow steady state to be achieved. However, occasionally an alternative route needs to be considered, for instance, in a patient who is profoundly edematous or whose subcutaneous sites break down very quickly. In these patients intravenous access might be needed, but other options might be to use sublingual, topical, or rectal medications if appropriate.

Crisis medications are usually charted for patients who are at risk of specific end-of-life emergencies, e.g., major bleeding, airway obstruction, seizure, and so on. In the hospital setting, prescribing such medications is intended to ensure that there can be a rapid and appropriate response, allowing the person to be sedated quickly to minimize distress. Doses of opioid and midazolam are most often prescribed, and they should be adjusted according to whether the person is opioid and/or benzodiazepine naïve or not. It is important to individualize and provide an effective dose to achieve sedation. Crisis medications should only be used for likely preterminal events. Prescribing crisis medications in residential aged care or for patients dying at home is more complex, as they may not be able to be rapidly administered and may take carers’ attention away from the dying person at the time they most need someone with them.

5.3 Review of Medications and Proportionate Dosing

Regular review and, if necessary, titration of medications is essential. Even when a patient is dying, medication doses need to be proportionate and defensible. Good palliative care involves careful choice of both drug and dose, according to the symptoms that are being experienced, and assessment of the benefits and any adverse effects (NICE 2015). Goals of treatment should be explicit, negotiated, and documented, for example, if sedation is the goal of care wherever possible that should be offered to and discussed with the patient (if they are able to communicate) and the family. Conflicting agendas may cause difficulties. For instance, patients and families may have concerns about euthanasia, or may be seeking assistance to hasten the person’s death, or alternatively may be fearful that inappropriate prescribing is causing the deterioration of their family member. Addressing these concerns is important in the palliative care context. As euthanasia and assisted death are being very widely discussed and are available in some jurisdictions, it is ever more important to be absolutely clear about the intent of all palliative treatments, particularly where they involve opioids or sedation.

5.4 Fundamentals of Psychosocial Care

A person who is aware that they are deteriorating or dying may have fears, worries, or concerns that they wish to discuss. It is important to ask about this and to identify who it is that they would most like to discuss any issues with. Another helpful question is to ask if the person has any important goals that they need assistance with. The general need for companionship and conversation varies greatly, and this should be explored, without making assumptions. Not everyone will be distressed or in need of companionship.

Supporting dying people may also involve conveying their wishes back to their family and other visitors and helping them to manage who and how many people visit and for how long. Some patients do not wish to be a burden on their family and friends and may seek to minimize time with them for that reason. It can sometimes be helpful in that situation to explain that for people who are likely to be grieving their loss, time spent now can be extremely precious and can help them to recover better during their bereavement. Some patients wish for spiritual support (Best et al. 2016) – whether it be from a minister or chaplain from their own faith community or simply a chance to discuss what is on their mind with a good listener. However, it is also quite
common for dying people to have no spiritual concerns or needs.

Be aware that in among all the end-of-life concerns, what many dying people greatly appreciate is to be treated more or less normally – to talk about what is going on in the world, in their family, to discuss the weather, or just to share a joke. As well as helping to normalize what is happening to them, such interactions can reconnect a person to their threatened sense of themselves, in a situation where much of their previous life and identity is vanishing. Many palliative care services have volunteers, pastoral care workers, or other team members who can support patients in this way, when the family struggling with their impending loss and the changes in the dying person may find it difficult to do so. Appropriately modified gym activities and diversional therapies that have the goal of supporting function are often not considered for dying patients, yet they can have great psychological value at this time, as patients may sometimes feel that they are “just waiting to die.” Dignity therapy (Ostlund et al. 2012; Guo and Jacelon 2014) at the end of life can be of particular benefit for dying patients whose sense of loss of personhood might otherwise overwhelm them. Even without such a specialized response, when a person is dying in an inpatient setting, every person that steps into their room has the opportunity to recognize and behave toward them in a way that supports their personhood. This is possibly one of the most therapeutic and under-recognized “interventions” in palliative care.

6 Management Decisions

Care for dying patients is anchored in the simplest principle of all. It is helpful to return regularly to the question of whether a given treatment, investigation, or procedure contributes anything to the comfort of the dying patient: any treatment or activity that does not add to the person’s comfort can be ceased. However, for many patients and families, such decisions may be difficult and confronting. Misunderstandings may cause conflict, for instance, related to a perception that a dying person is not being given the care that they need. Thus, part of the difficulty for many clinicians at this stage is how to work through these decisions with the patient and their family.

6.1 Stopping Medications and Investigations

When the irreversibility of the dying process is clear, then most long-term medications for comorbid conditions offer no benefit and indeed may create harm in terms of cost, burden of tablets, drug interactions, and greater risk of adverse effects as the dying patient becomes less and less able to eliminate medications (Stevenson et al. 2004; Currow et al. 2007). Once patients are no longer able to swallow, many of these decisions “make themselves.” However, discussion with patients and families is still very important, as ceasing medications can sometimes be seen as clinical fatalism or abandonment or may act as a confronting reminder of the imminence of death. When decision-making is individualized and explained, and when the rationale is the dying person’s comfort and well-being, it will usually be accepted.

Routine observations such as checking of blood pressure and pulse, or routine blood tests, also contribute nothing to the care of the dying patient, whose physiological parameters are likely to be abnormal. Investigations and observations at this time are only useful to answer specific clinical questions, and even then only if the answer that is yielded will be appropriate to act on for that patient. However, routine assessments of patients’ comfort, including of their pain, mental state, and other symptoms, and of how the person’s family are coping, should now become the focus of the daily care of the patient, replacing those clinical priorities which are no longer important. Some hospitals have attempted to address this shift in care processes by replacing standard patient charts with a specific “comfort chart” for dying patients.

For some medications, withdrawal or inability to take via an oral route can be associated with problems or symptoms which may need to be carefully considered, and sometimes replacement
with alternative treatments may be appropriate. Common examples of medications requiring some consideration are included in Table 1.

### 6.2 Food and Fluids

Issues related to giving food and fluids in the last days of life can be extremely contentious to deal with. Families may be greatly distressed by the perception that a patient is not receiving enough nutrition, believing that this is the reason for the symptoms that the person is experiencing. The human and relational significance of food and drink should never be underestimated by clinicians, who need to be able to talk comfortably and empathetically with families and about this issue. In the past, there has been a tendency to routinely cease hydration in dying patients, and indeed this was institutionalized within some end-of-life care pathways and became one of the aspects of the Liverpool Care Pathway that caused much difficulty when poorly or inflexibly implemented (NICE 2015). Requests for parenteral hydration by families of dying patients are common (Gent et al. 2015). Little evidence exists to support any benefit of such treatment; there is some low-level evidence to suggest that it may improve nausea, but it may worsen ascites, without improving delirium or thirst or survival (Raijmakers et al. 2011). Artificial nutrition for dying patients has also not been shown to prolong life or improve quality of life (Chow et al. 2016).

As with everything else in the terminal stage, the patient’s comfort is the best guide wherever possible. Most families can be helped to understand that eating is no longer a biological necessity for a dying person, but that small amounts of food and drink, when able to be tolerated, and if the patient wants them, may give some pleasure – which at this time is the main goal. Lack of appetite, nausea, swallowing difficulties, dyspnea, or fatigue may all be limiting factors in how much oral intake a dying patient will want. Families can be helped to make this assessment, recognizing that pushing a person to eat may cause them distress. Likewise fluids are for comfort for the patient. When dry mouth is a problem for

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### Table 1 Alternatives to some common long-term medications which can be used in end-of-life care

<table>
<thead>
<tr>
<th>Oral medication</th>
<th>Alternative management strategy for end-of-life care</th>
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<tbody>
<tr>
<td>Antineuropathic agents</td>
<td>Monitor for worsening of pain and titrate opioids to compensate</td>
</tr>
<tr>
<td>Anti-inflammatories or gout medications</td>
<td>Dexamethasone given subcutaneously may provide anti-inflammatory cover if clinically required</td>
</tr>
<tr>
<td>Anticonvulsants</td>
<td>A patient who is on anticonvulsants after having had seizures should be converted to a long-acting benzodiazepine such as clonazepam. If anticonvulsants were prophylactic only, as needed doses of clonazepam should be made available, but the patient may not require regular doses</td>
</tr>
<tr>
<td>Anti-parkinsonian medications</td>
<td>Subcutaneous apomorphine or topical rotigotine may be appropriate for patients with severe Parkinson's disease even in the terminal phase, to prevent them becoming locked-in by immobility</td>
</tr>
<tr>
<td>Oral laxative</td>
<td>Consider treatment per rectum if clinically indicated</td>
</tr>
<tr>
<td>Anticoagulants</td>
<td>It is usually appropriate to cease anticoagulants, particularly if they are prescribed for prophylaxis. However, if deep venous thrombosis is a cause of distressing pain, it may be appropriate to cautiously continue parenteral anticoagulants such as low molecular weight heparin, depending on the clinical situation</td>
</tr>
<tr>
<td>Oral hypoglycemics, long-acting insulin, or other diabetic medications</td>
<td>When oral intake is minimal, regular oral hypoglycemics and long-acting insulins should cease. Frequent testing of blood sugar is not required. Hypoglycemia presents a more significant risk than hyperglycemia. Check blood sugar if symptomatic, and treat with short-acting insulin for symptom control if required</td>
</tr>
</tbody>
</table>
palliative care patients, which it commonly is because it is such a common side effect of many palliative medications, the best treatments are good, frequent mouth care and safely offering oral fluids. Parenteral hydration does little to help with this subjective experience (Raijmakers et al. 2011), but regular small sips of fluid, ice, mouth sprays, or topical administration of artificial saliva may be much more beneficial. Whenever appropriate, families can be encouraged to offer these, which can alleviate some of their own distress. However, it is also important to give some instruction about how to offer food and fluids safely, as many family members are unaware of the risks of aspiration for seriously ill patients. The idea of pleasure from oral intake can be further explored, encouraging the family to think about what the person might enjoy, for example, a frozen fruit or some ice cream, a sip of alcohol, or some soda water or lemonade.

Frequently in hospital, dying patients have been identified as being at high risk of aspiration and have been made “nil by mouth.” In the palliative care context, this is usually inappropriate; however, some institutions have policies that are quite rigid once such an assessment has been documented in the medical record. The alternative is to allow and assist the patient and family to make an informed decision about what oral intake they wish to have, including whether and when they wish to use thickened fluids and modified texture foods or not. For patients who want to eat or drink specific things, wherever possible they should be allowed to do so with safety precautions, which include careful positioning, ensuring that the patient is alert when eating or drinking, and offering only very small amounts at a time (Pollens 2004).

### 6.3 Appropriate and Inappropriate Interventions for Dying Patients

Stopping treatments is often much harder than starting them. Clinicians should carefully consider clinical endpoints and prognosis whenever they offer any active interventions at the end of life. When interventions are given for nonreversible problems, it is likely that those treatments will need to be withdrawn subsequently. Consideration of how to manage that is as important as initiating the treatment itself; for example, withdrawal of ventilation can itself be regarded as a palliative intervention (Huynh et al. 2013).

Many problems are not reversible in the terminal phase, for example:

- Fatigue and weakness in the terminal phase cannot be relieved by transfusion of red cells or correction of iron deficiency.
- Metabolic derangements in patients dying of renal or liver disease are not correctable.
- Severe cachexia and hypoalbuminemia are not able to be reversed by artificial nutrition.

Even when it is possible to correct biochemical or hematological abnormalities, this almost invariably does not produce any meaningful clinical benefit for the patient and is not able to be sustained.

Some potentially reversible problems may be considered for treatment if they improve the comfort of the patient and treatment is not too burdensome, for example:

- Hypercalcemia causing confusion.
- Respiratory tract infection causing coughing of purulent sputum.
- Seizures affecting mental state.
- Acute intercurrent conditions – for instance, gout, atrial fibrillation, cellulitis – can all be treated for the comfort of the patient rather than to prolong their life.

Some potentially reversible problems could potentially require a significant intervention, such as spinal cord compression, or obstructive processes that may be able to be relieved by stenting. The value of any such treatment, however, will completely depend on the life expectancy of the person and their ability to tolerate the procedure itself. For the dying patient, ongoing anticancer treatment – whether with chemotherapy, immunotherapy, or radiotherapy – is only of
value in the rare case that there is a defined symptom with likelihood of responding in the timeframe of the patient’s life expectancy, for example, SVC obstruction that can be treated with radiotherapy (Table 2).

### 6.4 Trials of Therapy

When there is uncertainty around the reversibility of a problem, for example, a patient with sepsis or delirium, and particularly when this problem makes it unclear whether the patient is in the terminal phase or not, it may sometimes be appropriate to offer a trial of therapy. The other context in which a trial of therapy can be appropriate is when a patient or family are absolutely insistent on receiving more active treatment which is unlikely to be of benefit. A trial of therapy involves a time-limited course of treatment, and an appropriate therapeutic outcome, specified in advance. In this context, functional outcomes that are meaningful to the patient are the most helpful, for example, “to be able to comfortably spend the day out of bed.” It may be important also to specify possible adverse effects of a treatment that would lead to stopping the trial. Discussing a trial of therapy for a patient who is approaching the terminal phase allows the clinician to be very clear about the context – which is that of very grave clinical concern – and thus can also help to prepare the patient and family for the possibility that death may happen soon. Often setting such clear goals gives patients and families a chance to adjust to their changing situation and can avert conflict about treatment, ultimately allowing them to be part of the decisions for a more palliative approach to care rather than fighting against them. Working through such a process carefully can help to maintain a strong therapeutic relationship, even where there is initial disbelief or great unreadiness for death.
7 Conclusion and Summary

Caring for patients at the end of life demands both clinical and human responses. This chapter has emphasized that none of the management approaches described should be allowed to become a rigid framework for care. Excellent care must always be grounded in evidence, but pathways and protocols are only ever a guide and on their own will not ensure that patients’ profound human needs are met. This was an important lesson from the implementation of the Liverpool Care Pathway (Neuberger 2013). The challenges of caring for dying people lie in how we respond to each circumstance, how we understand both the disease and the meaning of the disease, and in learning what dignity and comfort mean for each individual. Palliative care also cares for the family and loved ones of the dying person, during and after the death. This is a wide net and a serious responsibility. They too must be included in our care processes and decision-making to the very best of our ability.

Ultimately, our regular contact with death and dying should help us to be in safe hands for our dying patients, but never forgetful of the great human mystery we are witnessing. At the very end, we take them to that door, and stay with them, in order to see that they go through it safely. They depend on us to be their guide through a process that they have never experienced, but which we know familiarly.

References


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