



The Royal Australasian  
College of Physicians

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**Improving Care at the End of Life:  
Our Roles and Responsibilities**

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## Purpose

The Royal Australasian College of Physicians (RACP) is committed to advocating for improved end-of-life care.

The purposes of this Position Statement are to:

1. Promote high-quality patient-centred end-of-life care in both adult and paediatric medicine
2. Provide a definition of good end-of-life care, an overview of its key components, and measures for assessing the performance of good end-of-life care
3. Make recommendations that will form the basis of the RACP's advocacy work in this area
4. Inform the RACP's education curriculum and clinicians' Continuing Professional Development program
5. Influence stakeholders within and outside the RACP to work collaboratively to improve end-of-life care for all patients.

## Executive Summary

All physicians are likely to be involved in the identification and care of patients who are nearing the end of their lives. It is the responsibility of every physician to ensure that good patient-centred end-of-life care is delivered.

Physicians have a key role in providing clinical leadership to help patients to live well near the end of life and to proactively manage the dying process. This includes providing best practice palliative care and referral to specialist palliative care as and when required. Physicians also play a key role in promoting Advance Care Planning (ACP)<sup>i</sup> and participating in goals-of-care discussions. This includes discussions with the patient, and others of their choosing, relating to limitation of treatment and preferred place of care when the patient is nearing death.

Physicians are responsible for providing appropriate care (and referral if needed) so that patients at the end of life can be assured that their symptoms will be well managed and that their needs and those of their family/whānau<sup>ii</sup> will be met. However, delivering better end-of-life care requires effort and commitment from many stakeholders in both the public and private healthcare sectors, including doctors, nurses, allied health professionals, healthcare organisations, undergraduate schools, learned colleges, consumer groups, government and the community.

This Position Statement is based on a review of the literature as well as expert input from physicians working in this area. It also draws on results from a recent survey conducted by the RACP in early 2015 on Fellows' and trainees' attitudes towards, and knowledge and practice of, end-of-life care and ACP.

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<sup>i</sup> ACP is the process of planning for a person's future health and personal care. ACP helps ensure that an individual's choices for future medical treatment are respected, and their beliefs, values and preferences are made known, in order to guide future care in the event that the person is unable to make decisions or communicate. See Appendices G and H.

<sup>ii</sup> Māori term referring to the complete network of people supporting an individual or group.

It is clear from these sources that there are a number of barriers to good end-of-life care, including systemic and cultural issues, and areas for possible improvement in physicians' and other health professionals' practice, as well as in the broader healthcare system. This Position Statement sets out five elements that the RACP has identified as essential for the provision of good patient-centred end-of-life care:

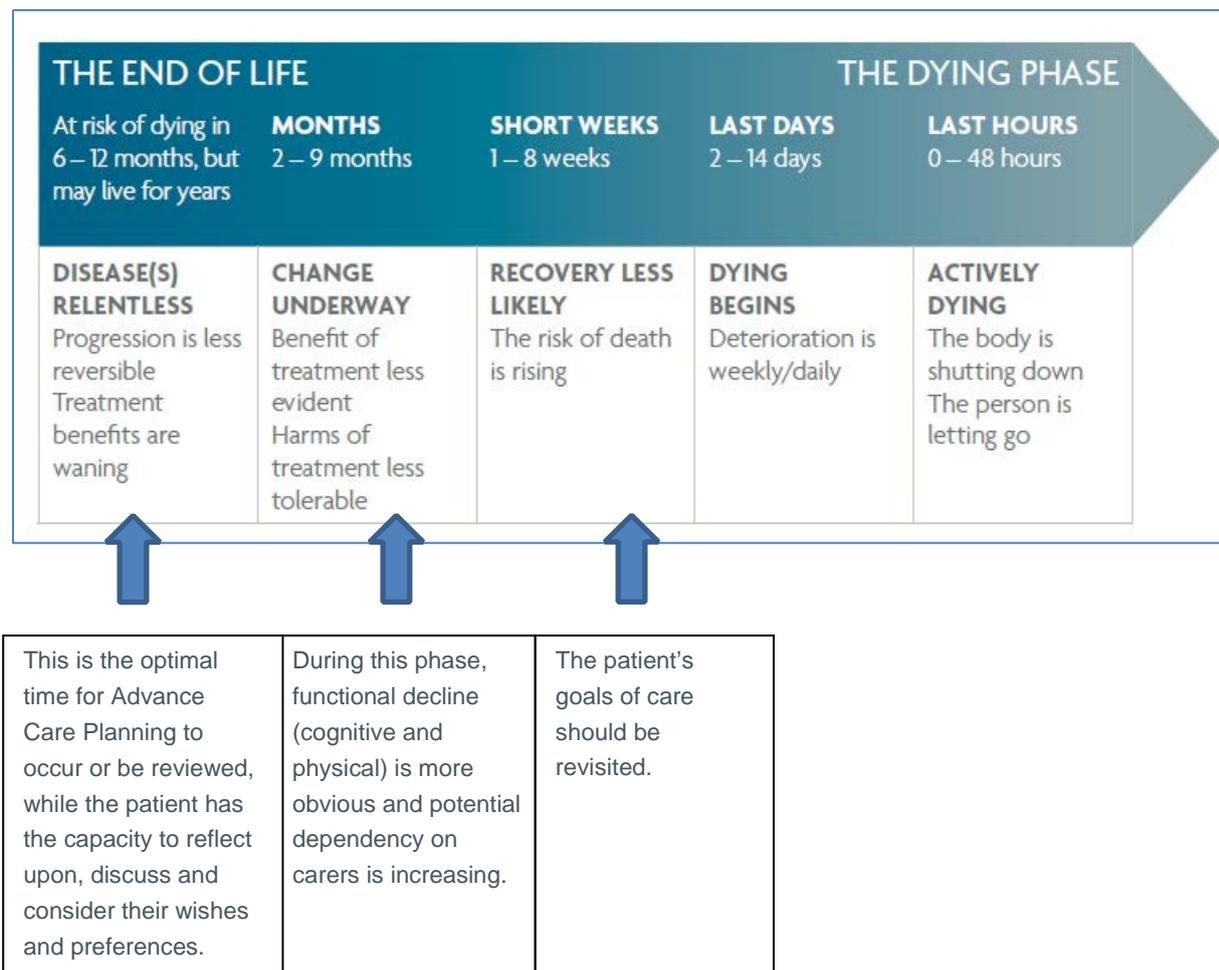
1. Diagnosing dying or the risk of dying
2. Respecting patient autonomy and supported decision making, and providing personalised care
3. Ensuring that medical treatment decisions respect the patient's best interests
4. Managing symptoms
5. Supporting carers and family/whānau.

A number of case studies, evidence-based tools and links to further resources are also included in this document to support physicians and other stakeholders in the delivery of high-quality end-of life care.

# 1. The end of life

People are ‘approaching the end of life’ when they are likely to die within the next 12 months, including when death is imminent.<sup>iii</sup> The right time to start planning for the end of life, and providing end-of-life care, can be uncertain: clinical deterioration may be unpredictable or reversible. However, good end-of-life care cannot be provided unless patients at risk of dying are correctly identified by their treating health professionals. All physicians should be able to diagnose a possible or probable end-of-life situation and help to initiate a shift from curative to supportive treatment.

Figure 1 illustrates common time frames in the dying process. It should be noted that these do not reflect all circumstances and that patients may be unwell and at risk of dying for many years, or may die much more quickly than anticipated.



**Figure 1: Timeframes in the dying process. Adapted from Department of Health UK (2013).<sup>1</sup>**

<sup>iii</sup> End of life: The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is uncertain or unknown. It may be as long as, or longer than, 12 months, as in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma. Australian Commission on Safety and Quality in Health Care (May 2015). National Consensus Statement: essential elements for safe and high-quality end-of-life care.

## 2. Challenges in end-of-life care

### The increasing prevalence of chronic disease

Technological, medical and public health advances in the past century have dramatically increased life expectancy in industrialised countries. Consequently, the age, mode, cause and place of death have changed significantly over that time. Sudden unexpected death is much less common than previously, with most people now dying after a variable period of decline from chronic disease, often with multiple co-morbidities and frailty.

Patients who are in the last year of their lives may receive input from a great number of medical and non-medical health professionals in a range of care settings (acute, community, public, private), and may present repeatedly. Ensuring that patients who are reaching the end of their lives have access to the right care at the right time by the right provider can be challenging but is fundamental to providing optimal care and maintaining patient dignity.

### A 'death denying' culture

Evidence shows that, too often, patients' wishes about their medical treatment at the end of life are unknown by their doctors and/or families.<sup>2</sup> One reason for this is that our culture is predominantly 'death denying'.<sup>3,4</sup> Discussing death and end-of-life issues may be uncomfortable and is sometimes taboo.<sup>5</sup> In a 2015 RACP survey, less than one in five respondents agreed that *most of the time doctors know the patient's preference regarding end-of-life care*.<sup>iv</sup>

Modern medical care tends to focus on curing, and restoring, which may sometimes conflict with accepting death as a natural event.<sup>6</sup> Like the population, physicians and other health professionals have diverse backgrounds and levels of experience with end-of-life care, and some may feel they have a duty to prolong life at all costs and/or see death as a medical failure.<sup>7,8</sup> For others, they may not realise their patient is nearing or at the end of life until very late.

Furthermore, fragmentation of care and lack of communication may mean that health professionals are unclear as to whose role it is to discuss end-of-life care with the patient.<sup>9,10</sup> There may also be a perception amongst some health professionals that palliative care and end-of-life discussions are less relevant or more difficult to broach for patients with non-malignant diseases, such as dementia, frailty, neurodegenerative disorders, and progressive cardiac or respiratory failure.

### Barriers identified by the RACP physician survey

The RACP's 2015 survey, which was drawn from a limited sample of volunteer and selected responders, found that the physicians and trainees felt comfortable and confident in discussing end-of-life issues and advance care planning. Although a majority of respondents had taken part in communication skills training, and many had completed training in ACP, they wanted to continue to improve their skills in these areas.

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<sup>iv</sup> The RACP's survey showed that only 17 per cent of respondents agreed with the statement "In your experience, most of the time doctors know the patient's preference regarding end-of-life care" and only 37 per cent of respondents agreed with the statement "In your experience, most of the time family members know the patient's preference regarding end-of-life care".

The responses to the survey also indicated that many patients nearing the end of life are provided with treatment that is inappropriate or against their wishes. About a third of respondents who care daily for patients likely to die within the next 12 months observed, at least weekly, treatment being given that was inconsistent with the patient's wishes. Furthermore, a third indicated they had observed, at least once per week, treatment being provided to patients that offered little chance of significant benefit.

Of all respondents, nearly a third had commenced an ACP conversation with a patient in the past six months, but a third reported they had not done any.

The survey identified the following potential barriers to undertaking ACP (in order of response rate):

- Time constraints
- Insufficient relationship with patients
- Health literacy of the patient or family/whānau
- Lack of skills of the doctor
- Discomfort in having end-of-life or ACP conversations
- Unavailability of appropriate place for discussions
- Patients aren't interested
- Language barrier.

Importantly, almost a third of respondents self-assessed that they lacked knowledge of legal frameworks for ACP. This may also be a barrier to speaking up when they observe treatment they believe is being provided against a patient's wishes.

If patients nearing the end of life are not identified and their needs and wishes are not respected, inappropriate and even harmful investigations and treatments may be provided in the last weeks, days or even hours of life. This can increase or prolong suffering for the patient and cause distress for the families, carers and health professionals. Furthermore, patients and families may not have the opportunity to prioritise activities and goals, or put their affairs in order, if they are unaware that death is likely in the near future.<sup>11</sup>

Further highlights of the RACP survey are included in **Appendix A**.

## **Issues surrounding euthanasia and physician-assisted death**

While it is not the aim of this Position Statement to address the issues of euthanasia or physician-assisted death, the RACP acknowledges that patients may raise these matters in the context of ACP or end-of-life discussions and that patients' concerns and the reasons for the request should be explored.

There is a diversity of views on these issues within the RACP and society at large. The RACP notes, however, that euthanasia and physician-assisted death are currently illegal in all Australian states and territories and in New Zealand (as at the date of publication of this statement).

For clarity, the following actions do not constitute euthanasia or physician-assisted death:

- a) Refusing life-sustaining treatments: patients with capacity have the right to refuse treatment including the provision of medically assisted nutrition and/or hydration.
- b) Withholding or withdrawing treatments that are not benefiting the patient: physicians have a duty to consider the benefits and harms of any treatments including the provision of medically assisted nutrition and/or hydration before instituting them. The benefits and harms of ongoing treatment should also be regularly reviewed. They should not be provided if they are not offering benefit to the patient.
- c) Providing appropriate palliative sedation to manage refractory symptoms.
- d) Titrating treatment to relieve symptoms.<sup>12</sup>

### 3. What is good end-of-life care?

Good end-of-life care<sup>v</sup> reflects a society that cares about its people.<sup>vi</sup> It is patient-centred, coordinated and focused on rational investigation, symptom management and de-prescribing. It involves early identification, assessment and treatment of pain and other suffering (physical, psychosocial, cultural and spiritual).<sup>13</sup> It enables patients nearing the end of life to live as well as possible, and then to die without unnecessary prolongation of the dying process. In all cases end-of-life care should be personalised to the individual patient and circumstance.

The quality of healthcare that patients receive towards and at the end of life can significantly impact on the surviving family/whānau and friends as well as the patient. Good end-of-life care ensures that the patient's family/whānau and carers are able to access support that they may need at this difficult time, and that bereavement support is also accessible.

Evidence shows that providing good end-of-life care leads to:

- a better quality of life for the patient before death<sup>14,15</sup>
- preservation of the patient's dignity<sup>16</sup>
- a better death from the perspective of the patient and their family/whānau
- less psychological burden on the patient, family/whānau, carers and health professionals<sup>17</sup>
- less pain, breathlessness and suffering caused by ineffective or inappropriate treatments<sup>18</sup>
- a reduction in costs associated with unwanted, inappropriate and ineffective treatment<sup>19,20</sup>
- an increase in the engagement and satisfaction of healthcare staff.<sup>21,22</sup>

The literature identifies a number of factors which characterise a 'good death'.<sup>23,24,25,26,27</sup> These can be used as a guide to physicians' and other health professionals' practices in their delivery of optimal patient-centred care to people nearing the end of life.

Tools for assessing and measuring good end-of-life outcomes can be found in **Appendix F**.

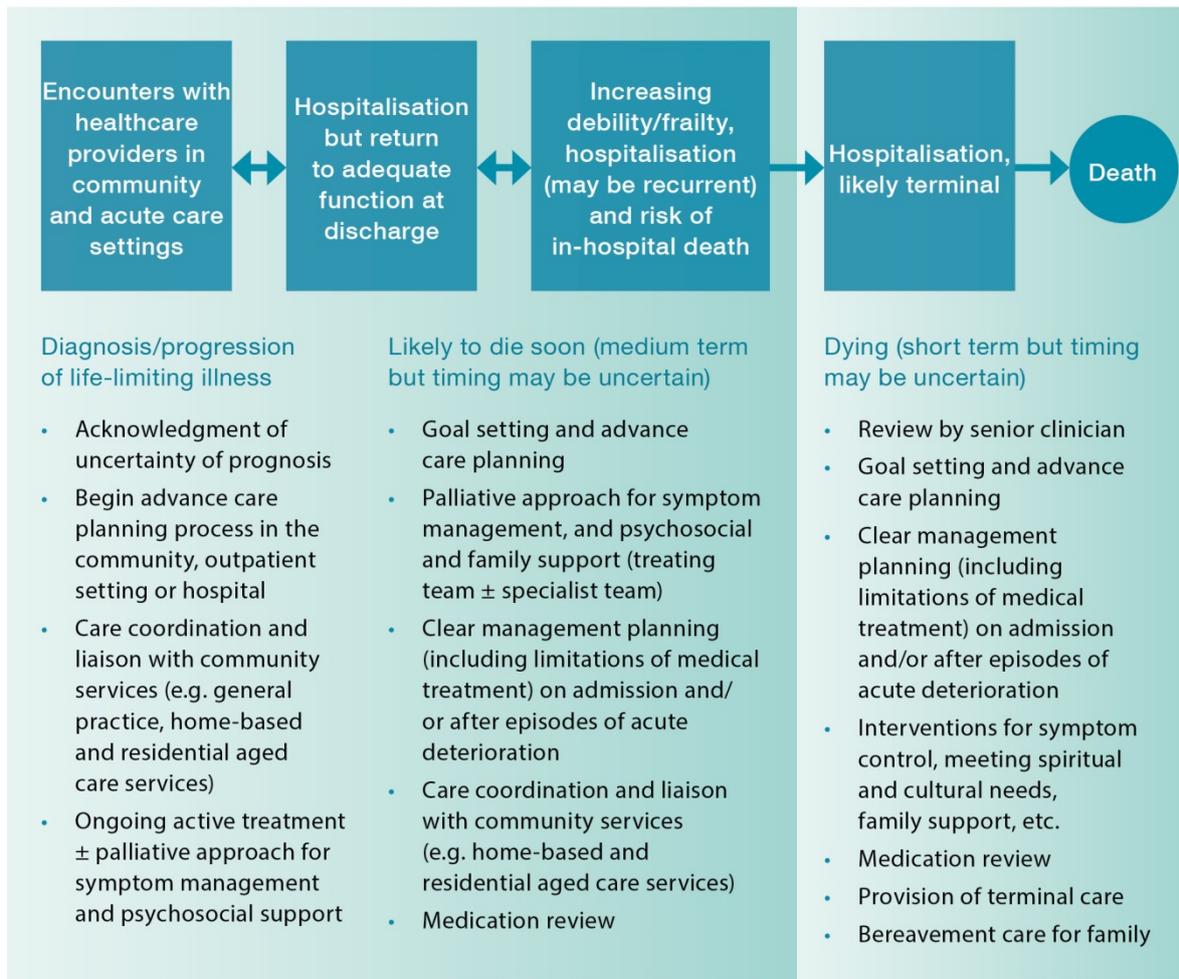
Figure 2 gives a broad outline of the various care components likely to be required at the different stages of end-of-life care. Doctors and other members of the healthcare team have a responsibility to ensure their patients can access these interventions if and when they are required, either by providing this care themselves, or referring patients to suitable services such as an ACP service, a specialist palliative care service or other services which support the patient, family/whānau and carers.

More information on specialist palliative care is located at **Appendix D**.

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<sup>v</sup> End-of-life care: The physical, spiritual and psychosocial assessment, care and treatment delivered by health professionals and ancillary staff to the patient at the end of life and their family and carers, and the care of the patient's body after their death. Australian Commission on Safety and Quality in Health Care, May 2015, National Consensus Statement: essential elements for safe and high-quality end-of-life care.

<sup>vi</sup> For further information about quality end-of-life care, refer to the Australian and New Zealand Society of Palliative Medicine Position Statement (February 2014). Quality end-of-life care – Part 1: Essential elements for quality, safety and appropriate clinical care at the end of life.



**Figure 2: Opportunities for end-of-life care interventions. Reproduced from Australian Commission on Safety and Quality in Health Care (2015).<sup>28</sup>**

## Specific patient groups

There are specific considerations for end-of-life care in certain patient groups.

- For children and adolescents particular attention is paid to their capacity to make decisions and the role of parents. End-of-life circumstances result from a greater mix of conditions and non-malignant disease, making diagnosing dying more complex. Guiding principles, case studies and useful references covering the circumstances surrounding end-of-life care for infants, children and adolescents are included in **Appendix E**.
- Patients with dementia may be unwell for many years and may progressively lose the ability to meaningfully engage in end-of-life discussions, so it is especially important that these conversations are initiated early while the person still has capacity.
- Patients with mental illness experience physical illness as much as, if not more than, the general population and, therefore, are entitled to the same commitment to ACP and good end-of-life care. Any opportunity to discuss and record their preferences should be used while

they have decision-making capacity. Written or verbally expressed preferences should be taken into account in medical decisions at the end of life and while the patient's illness impacts on their decision making.

- d) The cultural and linguistic diversity of Australia's and New Zealand's populations necessitates health professional flexibility and openness to differing attitudes, religions and cultural practices regarding ACP, decision making and end-of-life care, including post-death rituals. The diversity within cultural groups can be as great as between cultural groups. It is best, therefore, not to make assumptions, but to seek information from the patient and family/whānau and to use professional interpreters when appropriate.

Apparent conflict between some cultural behaviours and good medical practice can usually be dealt with and resolved by sensitive discussion (see **Appendix H**).

## 4. The elements of high-quality patient-centred end-of-life care

The RACP has identified five elements that are essential for the provision of good patient-centred end-of-life care:

1. Diagnosing dying or the risk of dying
2. Respecting patient autonomy and supported decision making, and providing personalised care
3. Ensuring that medical treatment decisions respect the patient's best interests
4. Managing symptoms
5. Supporting carers and family/whānau.

Each of these elements is discussed in turn in the sections below, and recommendations to improve the provision of good end-of-life care can be found at the conclusion of this document.

### Element 1: Diagnosing dying or the risk of dying

Diagnosing dying or the risk of dying is the essential starting point to providing good end-of-life care.

This element involves both proactively screening patients for those at risk of dying within 6–12 months and diagnosing patients in the 'active dying' stage, in their last weeks, days or hours of life, so that appropriate care can be provided. Diagnosing dying may be difficult, and prognosis can be uncertain. Physicians and other health professionals do not have to be absolutely sure before they start to think and talk about end-of-life care. They should acknowledge this uncertainty and discuss it openly with the patient and their family/whānau to facilitate awareness and discussion. It is not recommended to give definitive times until death as these may not be accurate and may cause additional distress.<sup>29</sup> Instead, patients and families should be supported to 'hope for the best, and plan for the rest'.

There are evidence-based tools, which are simple to use, that can help to identify a person who is at risk of dying in the next 6–12 months – some of these are detailed at **Appendix F**.

One of these tools, developed by the National Gold Standards Framework Centre in End of Life Care (UK), outlines three triggers that suggest patients are nearing the end of life:

1. The Surprise Question: 'Would you be surprised if this patient was to die in the next few months, weeks, days?' If not, then reassess the medical plan and talk to the patient.
2. General indicators of decline – deterioration, increasing need or choice for no further active care.
3. Specific clinical indicators related to certain conditions.<sup>30</sup>

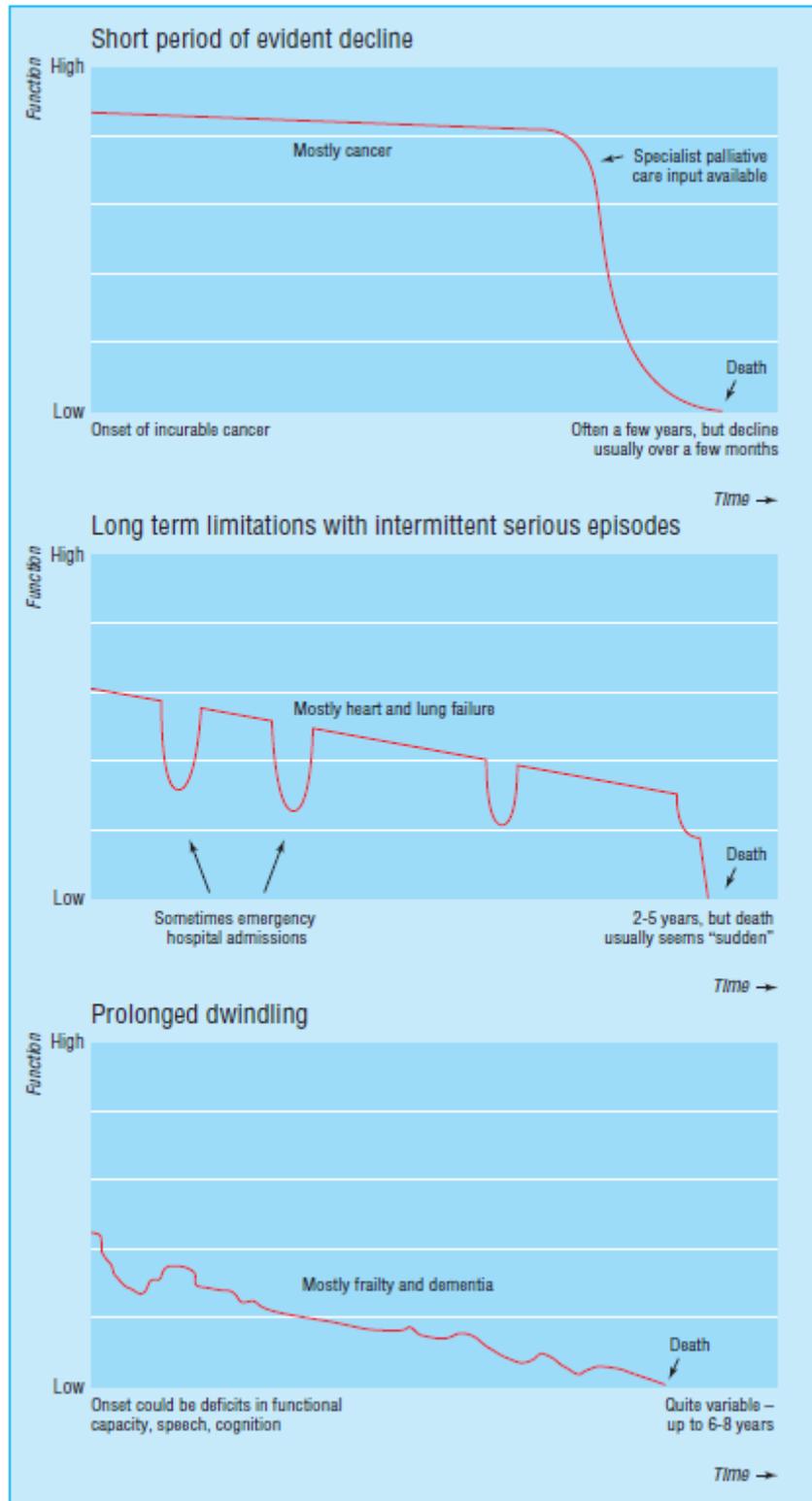


Figure 3: Typical illness trajectories for people with progressive chronic illness. Reproduced from Murray et al. (2013).<sup>31</sup> Adapted from Lynn and Adamson (2003) with permission from RAND Corporation, Santa Monica, California, USA.<sup>32</sup>

## The trajectories of decline

Today, most people will die from a terminal illness or one or more chronic illnesses that progressively interfere with their quality of life. Four trajectories of decline are commonly described. These are:<sup>33,34</sup>

1. *Sudden death*: unexpected, rapid death from causes such as trauma or acute myocardial infarction.
2. *Short period of evident decline*: long maintenance of good function despite diagnosis of a fatal illness, followed by a few weeks or months of rapid decline prior to death. Most weight loss and reduction in function occur in the person's last few months of life. Examples: many cancers (**Graph A, Figure 3**).
3. *Long-term limitations with intermittent serious episodes*: gradual decline in function, punctuated by episodes of acute deterioration that often result in hospital admission and the need for intensive treatment. While during each exacerbation there is a risk of dying, the person survives many of these episodes. The timing of death usually remains uncertain and may seem sudden and unexpected if prognosis is not reconsidered at each episode of disease exacerbation. Examples: chronic heart, lung or renal failure (**Graph B, Figure 3**).
4. *Prolonged dwindling*: long-term, progressive disability often from an already low baseline of cognitive or physical functioning. Death often follows a physiological challenge that would have been a less significant issue earlier in life, such as an infection (e.g. pneumonia, urinary tract infection) or a fall and fracture. Examples: frailty, dementia (**Graph C, Figure 3**).

Considering the likely disease trajectory and the patient's position on the trajectory may assist in identifying patients nearing the end of life and guiding ACP and goals-of-care discussions. Death at a particular stage along the trajectory or the rate of deterioration are uncertain.<sup>35</sup>

Regarding ACP and goals-of-care discussions, Murray et al.<sup>36</sup> note that

*the information offered and focus may vary depending on the trajectory and where the person is in relation to their trajectory. A person's treatment preferences may change as their illness progresses and they experience increased symptoms and have different experiences in relation to their health; hence there is a need to ensure appropriate opportunities to review advance care planning are available.*

Toward the end of life, repeated hospitalisation and exposure to health professionals provides opportunities for ACP and end-of-life discussions. Further information on ACP is provided in **Appendices C and G**.

**Recommendations** – see page 21.

## Element 1: Diagnosing dying or the risk of dying

### Case study 1: A 38-year-old patient with end stage metastatic breast cancer

Jane, a 38-year-old woman with three young children and working husband, is admitted to hospital with end stage metastatic breast cancer, very short of breath, with known multiple lung metastases. She had worsened on fourth line chemotherapy with no remaining treatment options.

She had not been referred to community palliative care earlier by her oncologist who felt that her condition was stable and that urgent contact was not needed. No advance care planning or real discussion of prognosis or realistic goals of care had taken place at this stage as it was felt that such discussion would take away from the patient's hope and could distress the children.

Jane is now diagnosed with pneumocystis pneumonia. Despite treatment, she deteriorates and is delirious and agitated. The family are distressed as they expected her to recover from this crisis and have been given mixed messages; she may be at risk of dying, but also that her current illness is treatable and that she should improve. The patient's husband becomes angry and finds it difficult to understand why this is happening. An urgent inpatient palliative care referral is made to provide support for this 'difficult' family.

The Palliative Care team review the patient, agree that she is dying and inform the oncology team that the patient is likely to die within the next few days. Her family are not aware of this. Her husband requests a review of all her treatment and an explanation about what is happening to his wife. The palliative care team suggest an urgent family meeting be convened to discuss prognosis, goals of care, end-of-life wishes and resuscitation plans.

However, before this meeting occurs, Jane arrests, undergoes full resuscitation, is admitted to ICU and dies 12 hours later.

### Reflective considerations

- Conversations about goals-of-care and end-of-life wishes should occur at sentinel points in the illness, e.g when metastatic disease is diagnosed, when further chemotherapy has failed, and when cancer is no longer considered curable. It is usually too late to have these discussions when the patient is critically unwell.
- This was a missed opportunity for Jane to prepare her children and the family for her impending death.
- Earlier palliative care referral (community and in hospital) could have assisted with:
  - discussion with Jane and her family about terminal care at home
  - better symptom control during the terminal phase
  - dying that was more dignified and peaceful.
- Uncertainty regarding benefits of life-prolonging treatment can be resolved by consulting the ICU specialist.

## Element 2: Respecting patient autonomy and supported decision making, and providing personalised care

Patient-centred care involves open communication with patients and their families regarding the likely prognosis of their illness and their goals of care, including the preferred place of care. It acknowledges uncertainties. Patients often wish to stay in control of their care, and to make the decisions that are right for them as far as practicable. To achieve this, their wishes need to be known. Therefore, they need to be supported to discuss their wishes with their health team and family/whānau, and to participate in their own care to the best of their ability<sup>vii</sup>, and as much as they desire.

ACP is a voluntary process which “informs and empowers patients to have a say about their current and future treatment”. This is especially important should they lose the capacity to make or communicate their own decisions about their end-of-life preferences<sup>37</sup>, and is a useful tool to document patient preferences at the end of life (for more information on this topic, see **Appendix C**).

Health professionals should initiate discussions about ACP with their patients and, where appropriate, assist the patient to complete advance care directives. Good communication with other treating health professionals, such as general practitioners, is vital to ensure coordination of ACP and to determine the most appropriate person to take responsibility for ACP. These discussions should be initiated early in the progress of a life-limiting disease where possible, and then be reviewed regularly.

If the patient lacks decision-making capacity, the health professional should discuss ACP with the patient’s family/whānau, specifically their substitute decision maker, to ascertain the patient’s previously expressed wishes. It should also be noted that the legal framework for ACP varies according to jurisdiction (see **Appendix G**).

Good communication skills are fundamental to providing patient-centred care that is responsive to the needs, values and preferences of the patient, particularly in the following areas:

- Ensuring that ACP is discussed and documented
- Sharing information across settings and teams through e-health records
- Minimising fragmentation of care by supporting one doctor or health professional to coordinate care of terminally or chronically ill patients.

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<sup>vii</sup> The Queensland Clinical Senate, in collaboration with Health Consumers Queensland, has produced *A charter for care of adult patients at the end of life* (2015). The RACP has endorsed this charter. It outlines a range of commitments from health professionals and patients to ensure good end-of-life care can be provided. It is available at: [www.health.qld.gov.au/publications/clinical-practice/engagement/qcs-patient-charter.pdf](http://www.health.qld.gov.au/publications/clinical-practice/engagement/qcs-patient-charter.pdf).

## **Element 2: Respecting patient autonomy and supported decision making, and providing personalised care**

### **Case study 2: A 58-year-old man on long-term dialysis**

Mario, a 58-year-old married man, was approached by a dialysis nurse trained in advance care planning (ACP) to consider his wishes if he became seriously unwell. With the support of his wife and his nephrologist, he considered and concluded that if he lost the ability to talk, walk and feed himself he would want dialysis and all other treatment to be discontinued but receive comfort care. He documented these views and preferences on an advance care plan which was witnessed by his wife and his nephrologist.

Approximately one year later, Mario presented to the emergency department with a large dominant hemisphere stroke. After three days of supportive treatment, the neurologist determined that little recovery was expected and that he would be left unable to speak, walk or feed himself. The neurologist, the nephrologist and Mario's primary nurse met with Mario's wife and a shared decision was made to not commence enteral feeding and to stop his dialysis. Mario died about one week later. Both specialist doctors and Mario's wife agreed that it would have been much harder, if not impossible, to stop Mario's treatment in the absence of the advance care plan and he would very likely have ended up in a nursing home with a PEG tube and being transferred to hospital for dialysis three times per week.

### **Reflective considerations**

- The discussion is the most important aspect, but documentation is very helpful when difficult substitute decisions need to be made.
- ACP is not to promote stopping treatment now but to plan for any future change in a person's condition.

**Recommendations** – see page 21.

## **Element 3: Ensuring that medical treatment decisions respect the patient's best interests**

Knowing when to withhold or limit treatment that is inappropriate or potentially harmful to the patient is a key component of good end-of-life care.

It is vital that healthcare professionals know and understand the law applicable in their jurisdiction and their obligations with regard to caring for patients at the end of life so they are able to make the best decisions for their patients, including withdrawing, withholding or limiting treatment where indicated. For further information on legal contexts, see **Appendix G**.

The 'best interests' standard of decision making requires the substitute decision maker to choose, from the treatments on offer, the treatments that they believe provide the maximum anticipated benefit

to the patient. It involves weighing the relative benefits, burdens and risks of different treatment options. “It requires the decision-maker to think what the ‘best course of action’ is for the person. It should not be the personal views of the decision-maker. Instead it considers both the current and future interests of the person who lacks capacity, weighs them up and decides which course of action is, on balance, the best course of action for them.”<sup>38</sup>

Unfortunately, even with the best of intentions, disputes may arise between patients, families, guardianship authorities and treating health professionals. There are also times when the patient’s wishes conflict with what their treating health professional believes to be their best interests. Good communication is essential to resolving such disputes and preventing their escalation. For further information on conflict resolution, see **Appendix H**.

### **Element 3: Ensuring that medical treatment decisions respect the patient’s best interests**

#### **Case study 3: An elderly woman admitted following a stroke**

Mrs Smith is an 87-year-old widowed woman admitted to a general medicine unit with a stroke resulting in a dense right-sided hemiplegia. Her speech is unintelligible and gag reflex compromised. She is alert and able to communicate non-verbally with her son, Jim, through nodding her head and squeezing his hand with her left hand.

With no improvement in her gag reflex after the first few days, a nasogastric tube (NGT) is inserted with Jim’s consent on a day when Mrs Smith is tired and not able to consent and the doctors want to start feeding. A day later she is noted to be unhappy with the NGT but is convinced by her son to leave it in. For the next few days she is often in tears as she points to the NGT. On Day 5, the NGT is found dislodged. Mrs Smith seems relieved but does not recall intentionally dislodging it. She refuses a second NGT. Meanwhile she is deemed unsuitable for rehabilitation due to her significant neurological deficits and is referred for placement in high-level residential care.

Mrs Smith does not have an advance directive but, based on the treating team’s impressions and after talking with her, the medical team feels that a second NGT insertion is not appropriate and that careful natural feeding and drinking should be permitted. Mrs Smith agrees but Jim is very concerned because his father died of aspiration pneumonia after being warned about ‘risk feeding’ and he and his mother had found the event very distressing. Jim reminds his mother of the complication and even asks, “You know you could die like Dad did?” Jim says that he felt guilty and responsible for his father’s death as he had fed him prior to him going into hospital. Mrs Smith signals that she understands the risk and is prepared to take the chance. She steadfastly refuses another NGT or consideration of a PEG tube.

The doctors can see Jim’s dilemma and explain that his mother has shown an understanding of her decision. They ask a speech pathologist and dietitian to explain to Jim that his mother will be helped to sit up and will be checked for alertness before being offered food of appropriate consistency. The

physician also talks to Mrs Smith about what she would want in the event that she developed pneumonia and she indicates that she would not want further treatment.

At her mealtimes, Jim observes that she seems at ease and he feels reassured she made the decision to continue natural feeding in the interest of her quality of life. Eventually Mrs Smith is transferred in a stable condition to residential care. An advance directive is prepared with her input and the guidance of a geriatrician.

#### **Reflective considerations**

- Wherever possible, individuals should be involved in decisions about their care at the end of life, even when this involves withholding or withdrawing life-sustaining interventions.
- The presence of an advance directive may enable this to occur if the person has lost capacity.
- Advance care planning also assists families when there are difficult decisions to be made and can assist in resolving possible doubt or guilt.
- A competent patient's supported decision, with consideration of the benefits and risks, is legitimate.
- Such discussions should also include what to do if the treatment trial fails.

**Recommendations** – see page 21.

### **Element 4: Managing symptoms**

Good management of symptoms is an ongoing component of good end-of-life care. Both cancer and non-cancer patients can have complex symptoms requiring good management. Symptoms can change as the condition of the patient progresses and as new or ongoing treatments or procedures are undertaken. There is a need for frequent review of function and symptom screening, as well as attention to non-physiological issues.

Particularly amongst patients with chronic diseases and co-morbidities, symptoms management can require the involvement of multiple treating practitioners. Physicians must be alert to signs of refractory symptoms and unmet needs, and seek assistance from palliative care specialists when needed.

The management of symptoms should be 'holistic' (physical, psychological and spiritual) and focus primarily, but not exclusively, on pain and shortness of breath as well as anxiety and depression. According to the Australian and New Zealand Society of Palliative Medicine (ANZSPM)'s statement on quality end-of-life care<sup>39</sup>,

*this process should be evidence-based and include a careful search for treatment side-effects or drug interactions and putting mitigating strategies in place (e.g. proactively manage constipation, nausea, cognitive impairment, fatigue, decreased function; reduce the risks of poly-pharmacy and institute rational de-prescribing processes based on harm/burden vs. benefit in the context of a realistic prognosis).*

## Element 4: Managing symptoms

### Case study 4: An elderly man with bone and liver metastases

Mr Stasov is an 87-year-old man admitted to hospital with progressive weight loss and extensive bone and liver metastases from an unclear primary. Various investigations are arranged, which will take several days to conduct. In the meantime, he reports severe ongoing pain, prompting his son, who is a nurse, to request for the palliative care team to see him.

When the palliative care specialist assesses him, she diagnoses two kinds of pain, from the liver capsule and bones, which will require different management. In addition, she identifies nausea and constipation as concerning symptoms. Once the symptoms are optimally controlled, the patient expresses existential concerns about the end of life.

At a family meeting that includes the palliative care nurse and the medical team, Mr Stasov reports severe fatigue and expresses a desire to have no further tests and to go home to die. He also expresses his fear of dying in pain but mentions that he has heard how addictive morphine is. He has also heard how “once you are on morphine you die quickly”. Following education about opioid myths, Mr Stasov’s symptoms are well managed and subsiding.

The palliative care team assists the patient’s discharge, organises community palliative care and informs his GP. Two weeks later the patient dies peacefully at home. The family expresses satisfaction with the whole process and the support of palliative care.

### Reflective considerations

- Exploring patient and family concerns is an important part of end-of-life management, including addressing myths about palliative symptom management.
- Understanding patient wishes for place of care at the end of life allows planning.
- Recognising that palliative symptoms are often multiple and thus complex and need careful multimodal palliative management is essential.
- Investigations, all of which have risks, should be avoided if they will not change management.

**Recommendations** – see page 21.

## Element 5: Supporting carers and family/whānau

Providing support to carers, family members/whānau and significant others, both before and after death, is an essential part of providing good end-of-life care. Their involvement (with patient consent) in discussions around prognosis, goals of care and ACP for the patient is an important element of this support. It becomes essential if the patient lacks the capacity to make his or her own preferences known.

As outlined in the ANZSPM Position Statement<sup>40</sup>, it is helpful for the healthcare team to document a list of close family members/whānau, loved ones and carers and to develop documented, evidence-

based support plans for them including bereavement follow-up plans. Validated assessment tools to assess bereavement risk can be used to identify how best to support families and carers (see **Appendix F**).

## **Element 5: Supporting carers and family/whānau**

### **Case study 5: A 67-year-old Somali patient with heart failure and poorly controlled diabetes**

Mr Ibráhim is a 67-year-old Somali patient who was admitted to hospital with worsening heart failure, poorly controlled diabetes and urinary sepsis. A chest x-ray reveals metastatic lung cancer but his heart failure is too severe to consider a biopsy or cancer treatment.

Mr Ibráhim's sepsis worsens despite treatment. On Saturday afternoon, following two medical emergency calls, the weekend physician makes a decision to not escalate further treatment. The patient's family are distressed and his son lodges a complaint as they believe that the medical team do not want to provide ongoing medical care for Mr Ibráhim and are letting him deteriorate because he has cancer.

A family meeting is called on Monday morning with the treating physician who, through an interpreter, explains to the family Mr Ibráhim's situation and about the end-of-life care he is now receiving. It emerges in the meeting that Mr Ibráhim has a large family who take turns to visit and help care for him in hospital. It turns out also that Mr Ibráhim and his wife have always deferred decision making to their son though there is no documentation of this. The son often misses seeing the treating team as he is working and cannot be present during ward rounds. Furthermore, their understanding of English is limited, leading to several misconceptions about Mr Ibráhim's condition.

The son is grateful for the meeting and thanks everyone for the ongoing care, and acknowledges that his father is dying. He asks how quickly the death certificate can be arranged after death and explains the religious rituals to be respected in caring for the body after death.

#### **Reflective considerations**

- The family's confusion and distress may have been avoided by preemptive discussions with them using an interpreter.
- Recognising the value of family meetings earlier and throughout the admission may have been beneficial.
- Cultural awareness may have helped in understanding the dynamics of this family and associated carers.

**Recommendations** – see page 21.

## 5. Embedding end-of-life care in medical education

End-of-life care is fundamental to the work of all physicians and other health professionals. Physicians must provide clinical leadership to embed the five elements of good end-of-life care into their practice, and to drive the cultural change that is needed to ensure that care is truly patient-centred and maintains patient dignity and respect.

Physician training is primarily delivered in workplace settings under supervision. Approximately 70 per cent of trainee learning is achieved through experience on the job, 20 per cent by observing role models including supervisors, peers and other health professionals, and 10 per cent through formal training. The RACP is committed to embedding the five elements of good end-of-life care into physician training and practice, and to assisting physicians and trainees to develop the skills needed to provide good end-of-life care to all their patients.

The RACP recognises the importance of trainees' professional development in end-of-life care. The RACP is currently reviewing the Basic Training curricula in Adult and Internal Medicine and Paediatric and Child Health with a view to integrating clinical knowledge with professional competence and embedding end-of-life care throughout the curriculum. A review of the 36 curricula in Advanced Training is also commencing.

The RACP is also developing Entrustable Professional Activities, the essential work activities that require the trainee to demonstrate skills across many domains of practice, including communication. An online module has been developed, focusing specifically on communication skills, including a scenario on end-of-life care and 'breaking bad news' to patients and family/whānau.

The RACP recognises the power of role models, and has developed a number of supervisor training workshops which include a focus on cultural elements such as modelling patient-centred care.

End-of-life care is a key priority for the RACP, and it will continue to be a focus area for policy and advocacy. It is essential that the perspectives of patients are included in both education and policy and advocacy. The RACP has engaged with an expert consumer group to ensure that the patient remains at the centre of all work on end-of-life care.

## Recommendations

The RACP has developed a number of recommendations to improve the delivery of end-of-life care. These are listed as they relate to various stakeholders and the five elements that the RACP has identified as essential for the provision of good patient-centred end-of-life care:

1. Diagnosing dying or the risk of dying
2. Respecting patient autonomy and supported decision making, and providing personalised care
3. Ensuring that medical treatment decisions respect the patient's best interests
4. Managing symptoms
5. Supporting carers and family/whānau.

### For all physicians in clinical practice

### Element(s)

#### Core skills

- |   |               |
|---|---------------|
| 1. Embed patient-centred end-of-life care as a core part of their practice.   | 1, 2, 3, 4, 5 |
| 2. Gain the skills to identify patients who are at risk of dying and their position on the trajectory to death, and promote the use of evidence-based tools to help identify patients in their last 6 to 12 months of life. | 1             |

#### Communication

- |  |            |
|--|------------|
| 3. Provide clinical leadership to sensitively, openly and honestly discuss and document prognosis, treatment, end-of-life care and the patient's preferences, needs and values.  | 1, 2, 4, 5 |
| 4. Support patients being cared for at home, including being accessible to provide advice to General Practitioners and community nurses who visit the home.  | 2          |
| 5. Actively seek to understand the wishes of patients nearing the end of life who are no longer capable of expressing them, including seeking documentation of advance care planning and consulting with family/whānau and carers. | 2, 3       |
| 6. Consult, involve and support the carers and family/whānau of a dying patient as required.   | 2, 3, 5    |

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## Planning ahead

- |   |         |
|---|---------|
| 7. Facilitate (or participate in) ACP discussions with patients and their important others, and assist with documentation of patient wishes if the patient so chooses. This includes communication and coordination with other treating health professionals such as General Practitioners. | 2       |
| 8. Commit to reviewing end-of-life care plans as these may change over time, taking into consideration the trade-offs between right place of care and other factors such as good symptom management and burden on family/whānau.  | 2, 3, 4 |
| 9. Utilise evidence-based support plans, including bereavement follow-up plans as required.   | 5       |

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## Management

- |   |   |
|---|---|
| 10. Manage symptoms holistically, utilising the best evidence available on benefits versus harms, and mitigating side-effects as far as possible. | 4 |
| 11. Regularly review symptom management.  | 4 |
| 12. Regularly review and de-prescribe medications which may harm, not enhance, comfort and quality of life or provide no realistic benefit.       | 4 |

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## For the RACP

### Advocacy and culture shift

- |   |               |
|---|---------------|
| 13. Champion the message that patient-centred end-of-life care is the responsibility of all physicians. This includes the capacity to identify patients near the end of life and provide or arrange an appropriate management plan. | 1, 2, 4       |
| 14. Lead a public conversation to promote awareness of good end-of-life care and a focus on quality of life rather than prolonging life by any means.   | 1, 2, 3, 4, 5 |
| 15. Advocate for the widespread adoption of Advance Care Plans and their use across the health system.  | 2             |
| 16. Foster a medical culture that supports open communication with patients, families and health professionals including questioning whether treatment is in the patient's best interest.   | 3             |
-

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## Education

- |   |               |
|---|---------------|
| 17. Embed the five elements of good end-of-life care into the curriculum to ensure all trainee physicians have the core skills to provide good end-of-life care.  | 2             |
| 18. Promote CPD to enhance physicians' skills in providing patient-centred end-of-life care and advance care planning.  | 2             |
| 19. Promote access to evidence-based educational and training resources and tools for physicians and trainees on: <ul style="list-style-type: none"><li>• Identification of patients in their last 6 to 12 months of life</li><li>• Communication skills, advance care planning and supported decision making</li><li>• Ethical and legal issues related to end-of-life care</li><li>• Managing the distress of patients, their families, carers and health professionals when caring for dying patients</li><li>• Appropriate prescribing and de-prescribing based on prognosis and burden/harm vs benefit of various treatment options</li><li>• Validated bereavement risk assessment processes and bereavement follow-up plans.</li></ul> | 1, 2, 3, 4, 5 |
- 

## For health system stakeholders

- |  |               |
|--|---------------|
| 20. Embed the principles of good patient-centred end-of-life care into health professional undergraduate and postgraduate curriculums and support ongoing training and development of sustainable models of care. This includes, but is not limited to, supporting systems changes to give health professionals the time they need to discuss end-of-life care with patients and to conduct and document family/whānau conferences including goals-of-care discussion, appropriate social work support, spiritual support, and bereavement care. | 1, 2, 3, 4, 5 |
| 21. Ensure patients can access specialist palliative care support as needed, at any time of day or night.  | 2, 3, 4, 5    |
| 22. Initiate and support systems changes to facilitate the identification of patients approaching the end of life.   | 1             |
| 23. Provide adequate resources in the community to support patients wishing to die at home, in a hospice or in a residential aged care facility.   | 2             |
-

24. Streamline patient information, including through e-health records, so that all health professionals involved in the care of the patient, whether in the public or private healthcare sector, have access to key information: discharge summaries, treatment and management plans (including information regarding substitute decision-maker appointments, advance care plans, goals-of-care plans, and resuscitation orders).	2, 3
25. Ensure that facilities have systems in place to receive ACPs and action them.	2
26. Harmonise legislation on ACP across jurisdictions.	2, 3
27. Minimise fragmentation of care in the health system by supporting one doctor or health professional to coordinate care of terminally or chronically ill patients.	2
28. Put in place systems to measure and benchmark outcomes of end-of-life care.	1, 2, 3, 4, 5

## **Appendix A: RACP 2015 online survey of Fellows' and trainees' knowledge, attitudes, practice and needs regarding advance care planning and end-of-life care**

This survey was initiated and designed by the RACP End-of-Life Working Party as part of the preparation of this Position Statement. It was undertaken to identify physician knowledge, attitudes, practice and needs regarding advance care planning and end-of-life care and to identify education requirements, facilitators and barriers regarding these subjects. The invitation to complete the 32-question online survey was emailed to a random sample of RACP Fellows and trainees, reflective of specialty distribution. In addition, palliative care Fellows and trainees were specifically targeted.

Of just over 1,500 respondents, half were male, almost half were aged 35–54, and over three-quarters worked in cities and in public hospitals. Just over half the respondents participated in adult medicine, and the remaining 45 per cent were in paediatric or palliative care practice or were trainees.

Two-thirds of respondents reported caring for patients with life-limiting illness or patients who were likely to die within 12 months. One-third of respondents observed, at least once a week, the provision of treatments that were inconsistent with known patient wishes and one-third observed, at least once a week, the delivery of treatments with little chance of significant benefit.

Questions on attitude revealed that more than four out of five respondents agreed or strongly agreed that ACP was worthwhile, relevant to patient care, and part of their role. Questions on knowledge showed that the majority of respondents correctly answered questions on patients' rights to refuse life-prolonging treatments, the right of the doctor to override an advance care directive and the doctor's obligation to provide aggressive treatment if requested by the patient/family/whānau.

Although the respondents stated that the majority of family/whānau members and doctors do NOT know the patients' wishes, in the last six months only one-third of physicians/trainees had commenced ACP with a patient on a weekly basis and less than one in ten had completed ACP with a patient on a weekly basis. Although most had undergone some training in communication skills and ACP discussions, and three-quarters felt comfortable in conducting these, just under half felt the need for additional training and more than four out of five stated that training in these areas should be mandatory.

Questions about perceived barriers to participating in ACP revealed that more than half of respondents considered time constraints to be a barrier and the remainder specified other barriers including inadequacy of the doctor–patient relationship, concern about the health literacy of the patient, inadequacy of the doctor's skills, and doctor discomfort with the conversation.

### **Conclusion**

The regular observation of treatment that was either of little benefit or was contrary to patient wishes confirms the inadequacy of current end-of-life care.

Although the majority of respondents reported comfort and skills with end-of-life care discussions and ACP, only a small proportion were holding or completing ACP discussions and the majority of respondents identified the need for further training in ACP and end-of-life communications.

## Appendix B: Suggestions for best practice outcomes for the provision of good end-of-life care

The following measures can be used to assess the delivery of a good death.<sup>41,42,43,44,45</sup>

- Are we adequately **managing the patient's symptoms**?
- Are we stopping non-beneficial treatments and **avoiding the prolongation of the patient's death**?
- Are we **enabling the patient to maintain control where possible** (over what happens, where death occurs, who is present and who shares the end, funeral arrangements, being kept informed and supported to make decisions etc.)
- Are we **enabling/assisting the patient to relieve burdens placed on the family/whānau**?
- Is the patient able to **strengthen relationships**?
- Are we **enabling the patient to maintain his/her dignity and privacy and to access spiritual and/or emotional support**?
- Are we **enabling the patient to make clear decisions**?
- Is the patient's **care being coordinated and integrated across settings and times** as far as possible/practicable?

If the above aspects of care are not met, good end-of-life care outcomes may not be achieved. In those instances, the primary doctor should review/reassess the care provided to the patient with the support of their team and consider whether to seek specialist palliative care support.

The National Consensus Statement suggests the following measures and methods for collecting data<sup>46</sup>:

Measures of the safety and quality of end-of-life care could include:

- Whether triggers to identify patients approaching the end of life were correctly used and applied
- Effectiveness of treatment of symptoms
- Documentation of the patient's wishes, and alignment of the patient's expressed wishes with actual care
- Real-time feedback on patient experiences of care
- Feedback on their experiences from families and carers of patients who received end-of-life care
- Whether any existing advance care directive or plan was enacted
- The category of death (expected/unexpected/diagnosis)
- The time lapse between deciding to palliate or referring to specialist palliative care, and death
- Transfers of care in the last week of life (e.g. transfers to or from intensive care).

Methods for collecting data could include:

- Retrospective audit of case notes (e.g. documentation of discussions, patient preferences, anticipatory plan of care and plan of care in the terminal phase; appropriateness and frequency of clinical observations)
- Medication chart safety review (e.g. to determine whether inappropriate medications were stopped, and palliative medications were prescribed and administered appropriately)
- Follow-up with families, carers, clinicians and other staff involved in the patient's end-of-life care
- Use of tools developed for specific settings (e.g. the Family Satisfaction in the Intensive Care Unit© survey)
- Multidisciplinary mortality and morbidity review.

All deaths should be routinely reviewed to determine whether the safety and quality of the patient's end-of-life care were acceptable, and how they could have been improved.

## Appendix C: Advance Care Planning (ACP)

ACP is the process of planning for a person's future health and personal care. ACP helps ensure that an individual's choices are respected for future medical treatment. Their beliefs, values and preferences are made known, in order to guide future care in the event that the person is unable to make decisions or communicate.

There are two main aspects to ACP:

- Appointing a substitute decision-maker
- Discussing (and preferably documenting in an ACP/Directive) a person's wishes for care. This may include documentation of values, beliefs and specific treatment preferences.

Formal ACP programs usually operate within a health, institutional or aged care setting after a life-limiting condition has been diagnosed, and frequently require the assistance of trained professionals. However, people can choose to discuss their advance care plans in an informal family/whānau setting.<sup>47</sup>

Evidence shows that **ACP improves:**

- Patient care, including end-of-life care
- The likelihood of a person's end-of-life wishes being known and respected by doctors and families
- Patient and family/whānau satisfaction with care
- Families' perceptions of quality of death
- The likelihood of a person dying in their preferred place
- Family/whānau preparedness for what to expect during the dying process.

Evidence also shows that **ACP reduces:**

- The likelihood of unwanted treatment at end of life
- The number of hospital admissions of people who would have preferred to stay in their home/residential aged care facility
- Stress, anxiety and depression in surviving relatives
- Distress amongst healthcare providers
- Ineffective or unwanted costly care at end of life without increasing mortality.<sup>48,49,50</sup>

As described by Scott et al.<sup>51</sup>,

*For ACP to become part of mainstream patient-centred care, accountable clinicians working in primary care, hospitals and nursing homes must effectively educate colleagues and patients about the purpose and mechanics of ACP, mandate ACP for all eligible patients, document ACP in accessible formats that enable patient wishes to accurately guide clinical management, devise*

*methods for reviewing ACP decisions when clinically appropriate, and evaluate congruence between expressed patient wishes and actual care received.*

Although ACP can potentially benefit everybody, some factors may make it more relevant for introducing or reviewing ACP with some people. These include:

1. When a person indicates that they would like to talk about their future care and treatment.
2. As part of routine care of people with medical conditions:
  - a) diagnosis of a new, significant or terminal medical condition
  - b) where there is a significant change in the person's medical condition, such as the need for home oxygen, significant deterioration in ability to perform activities of daily living, or deterioration in measurement of function on tests results
  - c) at key points in the person's illness trajectory, such as hospitalisation or after a life-threatening event
  - d) as part of a specific assessment, such as the 75+ health assessment or a comprehensive medical assessment
  - e) Where the answer is 'No' to the 'surprise question': 'Would you be surprised if this person died within the next 12 months?'
3. The person is at risk of losing capacity in the next 12 months – such as a diagnosis of early dementia or another progressive neurological disorder.
4. When there is a change in care needs such as the person becoming a recipient of a home care package or being admitted to a residential aged care facility.

## Appendix D: Specialist palliative care

### Specialist palliative care services are defined as:

*Services provided by an interdisciplinary team of specialist palliative care professionals, who have undergone specific training and/or accreditation in palliative care/medicine. Specialist palliative care services are provided in various care settings including community, home, hospitals, aged care homes and hospices and palliative care units. Specialist palliative care may be provided by hospice or hospital based palliative care services where patients have access to at least medical and nursing palliative care specialists.<sup>52</sup>*

Where possible and appropriate, early referral should be made to specialist palliative care services. But particularly in the terminal phase, it is important that specialist palliative care teams are involved with:

- Management of refractory pain, shortness of breath or other symptoms.
- Management of more complex depression, anxiety, grief and existential distress.
- Assistance with conflict resolution regarding goals or methods of treatment: within families, between staff and families, among treatment teams.
- Assistance in addressing cases of inappropriate care that some may define as 'near futility'.

Specialist palliative care is delivered in three key ways:

- **Directly** – to provide direct management and support of patients and families/whānau where more complex palliative care needs exceed the resources of the generalist provider. Specialist palliative care involvement with any patient and the family/whānau can be continuous or episodic depending on the changing need. Complex need in this context is defined as a level of need that exceeds the resources of the generalist team – this may be in any of the domains of care: physical, psychological, spiritual, etc.
- **Shared care** – where a patient is undergoing acute management of their chronic advanced disease, palliative medicine physicians and teams are also commonly asked to become involved to concurrently manage complex palliative care needs of the patient, or help the family/whānau and carers, or help facilitate complex discharge to community services and liaison with GPs and community nurses.
- **Indirectly** – to provide advice, support, education and training to other health professionals and volunteers to support the generalist provision of palliative care.

Specialist palliative care services will be using many of the following tools and processes to ensure high-quality and continuously improving outcomes in service delivery:

- Tools to proactively assess and measure treatment outcomes of symptom management, especially focusing on pain, shortness of breath, mood and spiritual issues of meaning and existential suffering, along with recurrent assessments of physical and cognitive function
- Frameworks to allow for rational prescribing and de-prescribing based on assessments of harm/burden vs benefit guided by the predicted prognosis

- Tools to proactively engage in advance care planning, goals-of-care discussions and documentation, and documenting preferred place of care (for terminal phase care)
- Tools to proactively elicit family/whānau/carer needs, assess bereavement risk, and develop adequate bereavement support plans
- Processes to coordinate care and manage clinical handover of care across team settings and time
- Processes to audit and continuously improve the quality of care for patients and carers for all expected deaths (mortality review process)
- Validated palliative care tools to gain adequate family/whānau/carer feedback on the quality of care provided using a methodology that meets the basic needs for randomised sampling to continuously improve service provision in line with consumer feedback.

### **What does a specialist in palliative medicine offer?**

Consultants in palliative medicine have undergone rigorous advanced training in palliative medicine through the RACP or have been recognised by the RACP as having undergone equivalent robust training under another recognised specialist training College. Palliative medicine is the study and management of patients with active, progressive and advanced disease, for whom the prognosis is limited and the focus of care is on their quality of life. Palliative care is best initiated to be provided early and concurrently with active disease management of an underlying chronic advanced illness.

Consultants in palliative medicine provide clinical leadership to specialist palliative care inpatient units, community and hospital palliative care teams, and day centres. Their role includes:

- Direct clinical care
- Providing advice to primary and secondary care colleagues
- Attending multidisciplinary teams for site-specific cancer and long-term conditions, e.g. chronic obstructive pulmonary disease (COPD), chronic congestive heart failure, etc.
- Running joint/parallel clinics with other specialists
- Service development.

### **When should a referral to specialist palliative care be made?**

Referral to specialist palliative care is recommended especially if:

- Symptoms are not being adequately managed as measured by proactive screening and use of appropriate outcome measurement tools.
- Goals of care, advance care planning and preferred place of care discussions between treating team members or with patients and their families/carers are becoming complex.
- Support for families/carers is hard to meet within current treating team structures and bereavement risk is likely to be moderate or high.

- Functional support is needed to keep patients at home and handover of care between settings and teams is becoming problematic.

Timely referral will support best practice management of pain and symptoms; identification of and support for complex psychosocial issues, with less incidence of depression; improved continuity of care with primary providers of palliative care; and the improved likelihood of good end-of-life planning resulting in decreased family/whānau/carer distress and decreased likelihood of complex grief. Such timely intervention also results in increased family/whānau satisfaction.<sup>53</sup>

# Appendix E: Paediatric palliative care

## Background

Providing end-of-life care for a child requires consideration of the following factors:

1. The death of a child is relatively uncommon in developed countries like Australia and this means that:
  - The expectations of families and the broader community of modern medicine are high.
  - The expectations of paediatric health professionals are high.
  - Discussing death and dying is difficult and is often avoided.
  - It is difficult for individual health professionals to acquire and maintain skills in discussing death and dying.
  - The community usually feels ill equipped to support the family/whānau of a dying child.
2. Children suffer from a diverse range of life-limiting conditions:
  - Malignancy accounts for only 25 per cent of this patient group.
  - A large proportion have neurodegenerative conditions that result in high levels of disability which worsen with time.
  - Some conditions are extremely rare, making prognostication difficult.
  - Many conditions are inherited and more than one child may be affected in a family/whānau.
  - The illness course is often long and unpredictable.
3. Developmental/neurological status affects:
  - How a child understands and communicates about their illness
  - Symptom assessment and management
  - Decision-making capacity
  - What is important in a child's life (e.g. school, kindergarten)
  - The pharmacodynamics of medications.
4. Parents have complex roles, as care-givers and proxy decision makers:
  - Parents and siblings have to live with the memory of the patient's end-of-life care for the rest of their lives.
  - Shared decision making minimises conflict and results in decisions that all parties can accept.

- The status and individual characteristics of the child and the parents should guide the style and pacing of communication with the child and family/whānau.
- The ongoing involvement of the child's paediatrician is important as he/she is often a key and trusted figure who brings specialist knowledge of the condition.
- A collaborative, multidisciplinary approach often offers valuable insights into the child and their family/whānau.
- Siblings require special attention.
- The service system involved in providing care to a child with a life-limiting condition may be complex and generally straddles hospital and community care.

In this Appendix are illustrative neonatal, paediatric and adolescent case studies followed by key references and resources.

### **Element 3: Ensuring that medical treatment decisions respect the patient's best interests**

#### **Case study 6: Neonatal**

*Adapted from Janvier A (2009). I would never want this for my baby. Ped Crit Care Med;10(1):113–114.*

When a mother is admitted at 23 weeks in labour, the on-call neonatologist tells the parents about the likely outcomes at this gestation and indicates that comfort care is an option, but the parents are not in favour of this and want “everything done”. A plan is agreed to offer full resuscitation. A baby girl is born, is intubated and transferred to the NICU. Initially she responds to being given surfactant and can be easily ventilated and looks pink and well. The parents are very happy and have named her Miracle, as this is what they are hoping for. The neonatologist tells them that babies at this gestation often do well in the first 12 hours, but that there is a realistic possibility she will deteriorate. She explains that she will meet regularly with them to discuss Miracle's progress. The parents, however, are very optimistic and are adamant that she “will make it, doctor, she made it to the NICU against all odds”, and do not want to hear anything negative. They are at Miracle's bedside all the time.

After 15 hours Miracle suffers a massive pulmonary bleed and she becomes extremely difficult to ventilate. She looks grey, mottled and sick. A head US scan reveals an extensive intracranial haemorrhage.

The neonatal team meets with the parents and suggests that continued intensive care is not in Miracle's best interest, that life support be stopped and Miracle be allowed to die comfortably. The parents refuse since nobody can tell them for sure that their daughter is dying. The neonatologist meets frequently with the parents and invites them to bring in other family members to help with decision making. A meeting takes place with close family, a pastoral care worker, with whom the parents have become close, and the palliative care team. All agree that it is time to stop the ventilator and start palliation, however the parents still do not want to withdraw ventilation.

Miracle continues to deteriorate. She has stopped passing urine, and needs vasopressor support and a morphine infusion for pain relief and sedation.

The neonatologist continues to talk with the parents, including about the resuscitation plan for Miracle. They still want CPR and adrenaline and finally agree to the offer of a brief period of CPR and one dose of adrenaline when Miracle's heart slows. Later, when the mother is cuddling Miracle, her heart rate is slowing down and the neonatologist is preparing to place her in the cot to start CPR, the parents ask for the tube to be taken out and to let her die. Miracle dies in her mother's arms after several minutes.

### **Reflective considerations**

- No matter how well you communicate, some parents still want "everything done". The only way forward is to keep the conversation going and show compassion and understanding at all times.
- It is important to clarify their expectations about the future, resolve any misunderstandings and try to correct unfounded or unrealistic expectations.
- Do not project your own expectations or wishes onto the parents. The memories of these precious hours will be with the parents for the rest of their lives.
- Listen more and talk less, but remember you are the patient's advocate.
- For parents who are struggling to "let go" it is ideal to find a middle ground for the benefit of the parents, but only if the comfort and dignity of the baby are not compromised.
- Involving family members or other persons of significance to the parents can be really important.

### **Case study 7: Paediatric**

*Adapted from Department of Health and Human Services (Victoria). Thinking ahead: a framework for planning care for children with life-limiting conditions (in press).*

Rose is nine years old and has the most severe form of cerebral palsy. She requires a wheelchair for mobility, a gastrostomy for feeding and is dependent on others for all her care. She is not able to communicate verbally but can express joy and pain. Rose suffers severe seizures from time to time despite anticonvulsant medication. She has a rapidly evolving scoliosis. She attends a special development school.

Rose has required a few admissions in the last 12 months for pneumonia, including one to intensive care where she required non-invasive ventilation. She found this distressing and the treating team discussed with her parents about how to manage future episodes.

Rose has been struggling at home for two months with increasing suction requirements. She has been tired and showing little interest in things that normally bring her pleasure. She has not been back to school. She presents to the Emergency Department (ED) with probable aspiration pneumonia and is in significant respiratory distress. The ED physician talks to the family about her clinical status and

tells them that he understands, from the documents he has read, that they are eager to give Rose an opportunity to recover but they don't want to burden her too much with interventions that might cause her distress. They confirm this and tell him the last two months have been very difficult for Rose.

Two days after admission, it is clear Rose is deteriorating and that she is really struggling with bilevel positive airway pressure (BiPAP) therapy. The parents say they don't know what to do. Rose's paediatrician reflects on the conversations they have had over time – how Rose loved school but can no longer attend, how they wanted to avoid unnecessary suffering at the end of her life and how they hoped she would be at home. She says that, based on this, it is her opinion that BiPAP should be stopped and the focus should now be exclusively on comfort. The parents agree and the previously completed advance care plan is altered to reflect the new goal. Arrangements are made for Rose to be cared for at home with the support of community palliative care and a specialist paediatric palliative care consultancy.

### **Reflective considerations**

- Advance care planning is a process that evolves over time.
- Discussions early in Rose's illness provided the foundation for effective decision making later on.
- The paediatrician used her clinical expertise and pre-existing relationship with the family to provide direction to the distressed parents when they needed it.

### **Case study 8: Adolescent**

John is a 15 year old with recurrent osteosarcoma of the thigh and lung metastases which have progressed despite chemotherapy.

He attends the oncology clinic, having missed two previous scheduled appointments. To the surprise of his accompanying mother, he describes a four-week history of pain in his left shoulder and right chest which he has managed with paracetamol and ibuprofen, with minimal effect, over the past two weeks.

John also reports an irritating cough, breathlessness with minimal exercise, fatigue and poor appetite. He has trouble sleeping due to worrying (which he does not wish to discuss further) and waking because of dyspnoea. He is referred to the paediatric palliative care team. Radiological evaluation shows further progression of the chest metastases and a moderate right pleural effusion.

His mother reports that John has largely retreated to his bedroom, spending most of his waking hours gaming on his laptop. The only time he has contact with his family (mother and 17-year-old sister) is during dinner. John's father has not been in contact with his children since separating nine years ago. His mother becomes tearful recounting her concern that John is depressed and how the only way he came to the clinic appointment was after she told him to "get off his arse cos we are going to the hospital". John ruefully replies that he is not depressed and he is just waiting to be told what he can

and cannot do.

He talks more freely after this and states that he worries about getting behind in schoolwork, not having enough energy to go out with friends and, finally, what is happening to him. After a conversation about his friends, John is asked if he wants an explanation of his symptoms, but he declines stating, "I know I am going to die." He is gently asked if he would like to know what this may look like. He declines, but his mother asks to be informed, which John agrees to. He also agrees to his mother making an advance care plan on his behalf although he wishes to give final approval once it is completed. John also wants his sister to be told what is happening but does not wish to see his father.

John is commenced on morphine and agrees to the effusion being tapped but not to having a chest drain inserted. He gains good relief from both measures and returns home two days later with support arranged through palliative care. John has one brief admission to the hospice three weeks later for management of pain resulting from him having stopped his opioid medication six days earlier. A chest x-ray shows a re-accumulation of the pleural effusion but John declines to have a further drainage.

John returned home, receiving community palliative care, and died eight days later with his family present.

#### **Reflective considerations**

- Adolescents and young adults are in a development phase involving increasing autonomy, but may still defer to their parents, including on advance care plan decision making.
- It is good to discuss the 'big stuff', but talking about the 'small stuff' like going out, drinking, hair loss is also important.
- Being upfront and clear builds trust, as does attending to the immediate problem.
- Adolescents and young adults cannot be pushed, even when time is limited, otherwise they are likely to just shut down.
- Adolescents and young adults are part of a family and what is distressing for them is distressing for their family.

## References and tools

Some useful references covering the unique circumstances surrounding end-of-life care for infants, children and adolescents include:

- Auckland District Health Board and Starship Children's Health (2010). Allow natural death – Te Wa Aroha. [www.starship.org.nz/media/292172/allow\\_natural\\_death\\_mar10\\_v2.pdf](http://www.starship.org.nz/media/292172/allow_natural_death_mar10_v2.pdf).
- Australian and New Zealand Intensive Care Society (2014). ANZICS statement on care and decision-making at the end of life for the critically ill. Edition 1.0. See Chapter 9 'Infants and Children'.  
[www.anzics.com.au/Downloads/ANZICS%20Statement%20on%20Care%20and%20Decision-Making%20at%20the%20End%20of%20Life%20for%20the%20Critically%20Ill.pdf](http://www.anzics.com.au/Downloads/ANZICS%20Statement%20on%20Care%20and%20Decision-Making%20at%20the%20End%20of%20Life%20for%20the%20Critically%20Ill.pdf).
- Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J, on behalf of the Royal College of Paediatrics and Child Health (2015). Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. Arch Dis Child;100(suppl. 2):s1–s23. doi:10.1136/archdischild-2014-306666.
- National Paediatric Palliative Care Clinical Network, supported by the New Zealand Ministry of Health (2015). Paediatric palliative care in New Zealand: clinical guidelines for end-of-life care. [www.starship.org.nz/for-health-professionals/national-paediatric-palliative-care-clinical-guidelines/#All](http://www.starship.org.nz/for-health-professionals/national-paediatric-palliative-care-clinical-guidelines/#All).
- Royal Australasian College of Physicians (2008). Decision-making at the end of life in infants, children and adolescents. [www.racp.edu.au/docs/default-source/advocacy-library/decision-making-at-the-end-of-life-in-infants-children-and-adolescents.pdf?sfvrsn=10](http://www.racp.edu.au/docs/default-source/advocacy-library/decision-making-at-the-end-of-life-in-infants-children-and-adolescents.pdf?sfvrsn=10).

## Appendix F: Evidence-based tools and resources

The following list of evidence-based tools and resources is not exhaustive but a good starting point. Arranged in accordance with the five elements, they can be promoted and used to assist provision of good end-of-life–care.

### Resources relevant across all elements

- Australian Indigenous HealthInfoNet. Palliative care. [www.healthinfonet.ecu.edu.au/related-issues/palliative-care](http://www.healthinfonet.ecu.edu.au/related-issues/palliative-care).
- CareSearch: palliative care knowledge network. [www.caresearch.com.au](http://www.caresearch.com.au).
- Palliative Care Curriculum for Undergraduates. [www.pcc4u.org/](http://www.pcc4u.org/).
- Palliative Care Outcomes Collaboration. Clinical manual. <http://ahsri.uow.edu.au/pcoc/clinicalmanual/index.html>.
- The Palliative Care Bridge. [www.palliativecarebridge.com.au/index.htm](http://www.palliativecarebridge.com.au/index.htm).
- Stanford Palliative Care Training Portal. <http://palliative.stanford.edu/>.

### Element 1: Diagnosing dying or the risk of dying

- Australian Commission on Safety and Quality in Health Care. Recognising and responding to clinical deterioration. [www.safetyandquality.gov.au/our-work/recognising-and-responding-to-clinical-deterioration/](http://www.safetyandquality.gov.au/our-work/recognising-and-responding-to-clinical-deterioration/).
- Clayton JM, Hancock KM, Butow PN et al. (2007). Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. MJA;186(12):77–108. [www.mja.com.au/journal/2007/186/12/clinical-practice-guidelines-communicating-prognosis-and-end-life-issues-adults#0\\_pgfid-1142446](http://www.mja.com.au/journal/2007/186/12/clinical-practice-guidelines-communicating-prognosis-and-end-life-issues-adults#0_pgfid-1142446).
- NSW Clinical Excellence Commission. AMBER Care Bundle. [www.cec.health.nsw.gov.au/programs/amber-care](http://www.cec.health.nsw.gov.au/programs/amber-care).
- The NHS Lothian and The University of Edinburgh’s Supportive and Palliative Care Indicators Tool (‘SPiCT Tool’). [www.spict.org.uk/the-spict/](http://www.spict.org.uk/the-spict/).
- The Royal College of General Practitioners (UK) Gold Standards Framework. [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk).
- The Waitemata District Health Board. Te Ara Whakapiri: Principles and guidance for the last days of life. Breaking bad news flowchart, p. 67. [www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life](http://www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life).

### Element 2: Respecting patient autonomy and supported decision making, and providing personalised care

- Advance Care Planning Australia. <http://advancecareplanning.org.au/>.
- Advance Care Planning (New Zealand). [www.advancecareplanning.org.nz/](http://www.advancecareplanning.org.nz/).

- AMA Victoria's Advance Care Planning Project (9 resource modules).  
[http://amavic.com.au/page/Member\\_Services/Policy\\_and\\_Media/Current\\_Projects/AMA\\_Victoria%E2%80%99s\\_Advance\\_Care\\_Planning\\_Project](http://amavic.com.au/page/Member_Services/Policy_and_Media/Current_Projects/AMA_Victoria%E2%80%99s_Advance_Care_Planning_Project).
- Australian Government Department of Health (2004). Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples: Resource Kit (prepared for the Australian Government Department of Health and Ageing by Mungabareena Aboriginal Corporation, Wodonga Institute of TAFE and Mercy Health Service Albury (Palliative Care).  
[www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm](http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm).
- Marie Curie Cancer Care (UK). Spiritual and religious care competencies kit.  
[www2.mariecurie.org.uk/documents/healthcare-professionals/spritual-religious-care-competencies.pdf](http://www2.mariecurie.org.uk/documents/healthcare-professionals/spritual-religious-care-competencies.pdf).
- Ministry of Health (2015). Te Ara Whakapiri: Principles and guidance for the last days of life. Spiritual care assessment tool based on FICA approach, p. 71.  
[www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life](http://www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life).
- NHS Scotland (2009). Spiritual care matters.  
[www.nes.scot.nhs.uk/media/3723/spiritualcaremattersfinal.pdf](http://www.nes.scot.nhs.uk/media/3723/spiritualcaremattersfinal.pdf).
- See **Appendix C**: Advance Care Planning
- See **Appendix G**: Legal contexts for Advance Care Planning

### **Element 3: Ensuring that medical treatment decisions respect the patient's best interests**

- See **Appendix G**: Legal contexts for Advance Care Planning
- See **Appendix H**: Conflict resolution
- Australian Medical Association (2014). Position statement on end of life care and advance care planning. <https://ama.com.au/position-statement/end-life-care-and-advance-care-planning-2014>.

### **Element 4. Managing symptoms**

- Care Search (2011). Symptom management at the end of life.  
[www.caresearch.com.au/caresearch/ClinicalPractice/Physical/EndofLifeCare/SymptomManagementattheEndofLife/tabid/741/Default.aspx](http://www.caresearch.com.au/caresearch/ClinicalPractice/Physical/EndofLifeCare/SymptomManagementattheEndofLife/tabid/741/Default.aspx).
- MacLeod R, Vella-Brincat J, Macleod S (2012). The palliative care handbook: guidelines for clinical management and symptom control, 6th edition.  
[www.hospice.org.nz/cms\\_show\\_download.php?id=377](http://www.hospice.org.nz/cms_show_download.php?id=377).
- Ministry of Health (2015). Te Ara Whakapiri: Principles and guidance for the last days of life, pp. 43–61. Includes guidelines and algorithms covering general principles of symptom management; nausea and vomiting; pain; respiratory secretions; delirium, restlessness or agitation; and dyspnea. [www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life](http://www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life).

- The Palliative Care Outcomes Collaboration. Symptom Assessment Scale, pp. 34–40. <http://ahsri.uow.edu.au/pcoc/sas/index.html>.

## **Element 5. Supporting carers and family/whānau**

- Hudson P, Remedios C, Zordan R, Thomas K, Clifton D, Crewdson M et al. (2010). Clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. Melbourne: Centre for Palliative Care, St Vincent's Hospital.
- Ministry of Health (2015). Te Ara Whakapiri: Principles and guidance for the last days of life. Bereavement information and assessment tool, p. 69. [www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life](http://www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life).

## Appendix G: Legal contexts for Advance Care Planning

Key components to legally recognised Advance Care Planning, for which legislative requirements vary between jurisdictions<sup>54</sup>, are:

- the appointment of a Substitute Decision Maker (SDM)
- the 'default' SDM if no SDM is appointed – this may be the spouse, close relative, carer or friend, and the order of priority varies according to jurisdiction
- the powers of the SDM and the principles which are to guide the decisions of the SDM
- the Advance Care Directive, or documentation of the person's wishes (which may include a legally binding refusal of treatment). Depending on the jurisdiction, this may be a statutory document or a document which may be recognised under common law. In some jurisdictions Advance Care Directives are binding, and in other jurisdictions they only inform decision making. Some jurisdictions may not recognise statutory Advance Care Directives from other jurisdictions.

Terminology varies according to jurisdiction. The following tables provide an overview of the situation in the Australian states and territories, and a brief outline of the New Zealand situation is given below. The Advance Care Planning Australia website (<http://advancecareplanning.org.au>) provides links to Australian state and territory health department resources, legislation and information in languages other than English.

### New Zealand

Patient rights are described in the New Zealand Code of Consumer Rights, including issues related to advance directives, which are not required to be in a formal written format. Under the *New Zealand Bill of Rights Act 1990* (section 11) patients can refuse treatment, and failure to respect such a refusal is a criminal offence.<sup>55</sup>

**Table 1: Appointed substitute decision maker (SDM). Reproduced with permission.<sup>56</sup>**

ACT, Australian Capital Territory; NSW, New South Wales; NT, Northern Territory; Qld, Queensland; SA, South Australia; WA, Western Australia; 1+ SDM: one or more substitute decision maker(s)

<sup>A</sup> From September 2015.

<sup>B</sup> 'Jointly' means the attorneys must all agree to any decisions and every document must be signed by all attorneys; 'jointly and severally' means that any of the attorneys can make a decision and sign documents together or without the others.

Jurisdiction									
	ACT	NSW	NT	Qld	SA	Tasmania	Victoria		WA
Name of appointed SDM	Enduring Power of Attorney (Healthcare Matters)	Enduring Guardian	Decision Maker (Healthcare Matters)	Enduring Power of Attorney (Personal Matters)	Substitute Decision Maker	Enduring Guardian	Enduring Power of Attorney (Medical Treatment)	Enduring Power of Attorney (Personal Matters) <sup>A</sup>	Enduring Guardian
Powers that can be granted and exceptions	Any decision relating to health care matters that the person could have lawfully made	Decisions relating to the appointer's lifestyle and personal matters, including consent to medical treatment	Any decision relating to health care matters that the person could have lawfully made	Any decision relating to personal matters that the person could have lawfully made	Any decision relating to health care matters that the person could have lawfully made	Decisions relating to the appointer's lifestyle and personal matters, including consent to medical treatment	Consent to, and refusal of, medical treatment on behalf of the appointer	Any decision relating to personal matters that the person could have lawfully made	Decisions relating to the appointer's lifestyle and personal matters, including consent to medical treatment
Can powers be limited by instrument?	Yes, can provide directions, limitations and conditions	Yes, can specify which powers are conferred	Yes, can specify which powers are conferred	Yes, can set terms for the power given	Yes, can include conditions of appointment	Yes, can specify conditions upon appointment	No	Yes, can place conditions or give instructions	Yes, can limit the powers and provide directions
How many people can be appointed?	1+ SDM	1+ SDM, 1+ alternative SDM	1+ SDM	1+ SDM	1+ SDM	1 or 2 SDM, 1 alternative SDM	1 SDM, 1 alternative SDM	1+ SDM	1+ SDM, 1+ alternative SDMB
How can multiple SDMs act together?	Jointly, severally <sup>B</sup> or in any other manner	Jointly, severally, or jointly and severally <sup>B</sup>	Jointly, severally, or jointly and severally <sup>B</sup>	Jointly, severally <sup>B</sup> , by majority or in any other manner	Jointly and severally <sup>B</sup>	Jointly	N/A	Jointly, severally, jointly and severally <sup>B</sup> or by majority	Jointly

Jurisdiction									
	ACT	NSW	NT	Qld	SA	Tasmania	Victoria		WA
Who can be appointed?	An adult	An adult who is not a paid medical provider, paid accommodation provider or paid carer for the appointer, or the spouse, parent, child or sibling of one of these	An adult (if someone <18 years is appointed it comes into effect once they turn 18 years)	An adult who is not a paid medical provider, paid accommodation provider or paid carer for the appointer	An adult who is not a paid medical provider or paid carer for the appointer	An adult who is not a paid medical provider for the appointer (and if they become one the appointment lapses)	No specified requirements	An adult who is not a paid medical provider, paid accommodation provider or paid carer for the appointer	An adult
Form	In the approved form	In, or to the effect of, the approved form	In the approved form or in writing according to requirements	In the approved form	In the approved form	In, or to the effect of, the approved form	In the approved form	In the approved form	In, or to the effect of, the approved form
Registration			Optional registration			Must be registered			
Signature and witness requirements	Appointer's signature must be witnessed by two witnesses, one of whom must be authorised to witness statutory declarations; must be signed by the appointee	Appointer's and appointee's signatures must be witnessed by one or more eligible witness (lawyer or registrar of local court)	Appointer's signature must be witnessed by an authorised witness (a person authorised to administer an oath); must be signed by appointee	Appointer's signature must be witnessed by an eligible witness (justice of the peace, commissioner for declarations, lawyer, notary public); must be signed by appointee	Appointer's signature must be witnessed by an eligible witness (from published list of categories) and also not a beneficiary of the appointer's will, the appointer's health practitioner or someone paid to care for the appointer; must be signed by appointee	Appointer's signature must be witnessed by two witnesses who are not related to the appointer or appointee; appointee not required to sign	Appointer's signature must be witnessed by two witnesses, one of whom is authorised to witness statutory declarations; appointee is not required to sign (is actually prohibited from signing as a witness)	Appointer's and appointee's signatures must be witnessed by two witnesses, one of whom must be authorised to witness affidavits or is a medical practitioner	Appointer's and appointee's signatures must be witnessed by two witnesses, one of whom must be authorised to take declarations

**Table 2: Default substitute decision makers (SDM). Reproduced with permission.<sup>57</sup>**

ACT, Australian Capital Territory; NSW, New South Wales; NT, Northern Territory; Qld, Queensland; SA, South Australia; WA, Western Australia

Jurisdiction	Terminology for Default SDM	Hierarchy			
		1st	2nd	3rd	4th
ACT	Health Attorney	Domestic partner	Carer for the person	Close relative or close friend	
NSW	Person responsible	Spouse	Carer for the person	Close friend or relative	
NT	n/a				
QLD	Statutory health attorney	Spouse	Carer for the person	Close friend or relative	
SA	Person responsible	Prescribed relative <sup>A</sup>	Close friend	Carer for the person	
Tasmania	Person responsible	Spouse	Carer for the person	Close friend or relative	
Victoria	Person responsible	Spouse or domestic partner	Primary carer	Nearest relative	
WA	Person responsible	Spouse or de facto partner	Nearest relative with close relationship	Primary provider of care	Any other person with close personal relationship

<sup>A</sup> Any of: legally married to the person; domestic partner; related by blood or marriage; related by adoption; related according to Australian and Torres Strait Islander kinship rules.

**Table 3: Decision-making requirements. Reproduced with permission.<sup>58</sup>**

ACT, Australian Capital Territory; NSW, New South Wales; NT, Northern Territory; Qld, Queensland; SA, South Australia; WA, Western Australia; SDM, substitute decision maker; ACD, advance care directive; AHD, Advance Health Directive

Jurisdiction		Decision-making principle
ACT		The person's wishes must be given effect to, unless this is likely to significantly adversely affect the person's interests, in which case the person's wishes must be given effect to as far as possible.
NSW		Medical and dental treatment should only be carried out for the purpose of promoting and maintaining the person's health and well being. General principles include that the welfare and interests of such persons should be given paramount consideration, and that the freedom of decision and freedom of action of such persons should be restricted as little as possible.
NT	Substituted judgement	Decision makers must give effect to any existing advance care statement. If no advance care statement exists, they must exercise substituted judgement, defined as exercising their decision-making power in a way the decision maker reasonably believes the person would have done in the circumstances. If the decision maker is unable to form a reasonable belief about what the person would have done in the circumstances, they must make a decision in the way that they reasonably believe is in the person's best interests.
Qld	Substituted judgement	The principle of substituted judgement must be used, taking into account, to the greatest extent possible, the person's views and wishes. In addition, powers must only be exercised if necessary and appropriate to maintain or promote the person's health or well being and, in all circumstances, in the adult's best interests.
SA	Substituted judgement	Decisions should be made based on substituted judgement, making decisions the SDM reasonably believes the person would have made under the circumstances. The SDM must give effect to any instructions or directions expressed in an ACD, and seek to avoid any outcome or intervention that the person would wish to be avoided. In the absence of any specific instructions or expressed views, decisions must be consistent with the proper care of the person and the protection of his or her interests.
Tasmania	Best interests	The person responsible may consent to medical treatment that is in the best interests of the patient. The paramount factor of best interests is the patient's wishes.
Victoria	Best interests	The person responsible must act in the best interests of the patient. The paramount factor of best interests is the patient's wishes.
WA	Best interests	Treatment decisions included in an AHD must be decided in accordance with the AHD. In the absence of an AHD, the person responsible must make decisions according to their opinion of the best interests of the person. This includes taking into account the wishes of the person as far as possible.

**Table 4: Expression of health care wishes: statutory documents. Reproduced with permission.<sup>59</sup>**

AHD, Advance Health Directive; EPA, Enduring Power of Attorney

Jurisdiction	Document Name	What can it contain?	Form	Registration	Requirements to be valid
ACT	Health Direction	Direction about the withholding and/or withdrawal of medical treatment	In writing, orally or in any other way		Maker's signature must be witnessed by two people; if non-written, witnesses must be two health professionals present at the same time where at least one is a doctor
NT	Advance Personal Plan	Advance Consent Decisions to expressly consent or refuse consent for health care (must be followed), and advance care statements (which influence substituted judgement decisions)	Must be in the approved form or in writing according to regulations	Optional registration	Maker's signature must be witnessed by an authorised witness
NT	Direction under Natural Death Act (superseded; before 17 March 2014)	Refuse extraordinary measures if the person is suffering from a terminal illness	Must be in the approved form		Maker's signature must be witnessed by two adults, neither of whom are a medical practitioner responsible for the treatment of the person
Qld	Advance Health Directive	Record of wishes, directions about health matters and/or special health matters and information about these directions; directions refusing life-sustaining measures are only valid if the person's health is sufficiently poor and they have no reasonable prospect of regaining capacity	Must be in the approved form or in writing in accordance with regulations		Maker's signature must be witnessed by an eligible witness; must be accompanied by a certificate signed and dated by a doctor stating the person had capacity to make the AHD
SA	Advance Care Directive	Record wishes and decisions about future health care, residential and accommodation arrangements and personal affairs; binding provisions to refuse particular health care, non-binding provisions for anything else	Must be in the approved form		Maker's signature must be witnessed by an eligible witness, excluding the person's health practitioner or someone paid to care for them; must be in English

Jurisdiction	Document Name	What can it contain?	Form	Registration	Requirements to be valid
SA	Anticipatory Direction (superseded; before 1 July 2014)	Directions as to medical treatment the person does or does not want if they are in the terminal phase of a terminal illness or in a persistent vegetative state and lack capacity	Must be in the approved form		Maker's signature must be witnessed by an authorised witness
Tasmania	Enduring Guardianship	Enduring Guardianship appointment can include conditions of appointment where decisions about medical or personal care can be included that the Enduring Guardian must comply with	Must be in the approved form	Must be registered	Maker's signature must be witnessed by two witnesses, who are not related to the individual or the Enduring Guardian
Victoria	Refusal of Treatment Certificate	Refusal of medical treatment (generally or a particular kind) for a current condition	Must be in the approved form		Maker's signature must be witnessed by two witnesses, one of whom must be a registered medical practitioner; can also be completed by the person's EPA (Medical Treatment) or a court-appointed guardian
WA	Advance Health Directive	Document treatment decisions with regard to future health care	Must be in, or substantially in, the approved form		Maker's signature must be witnessed by two witnesses, one of whom must be authorised to take declarations; person should be encouraged to seek legal or medical advice

## Appendix H: Conflict resolution

The text below is an extract from the Executive Summary of the Australian and New Zealand Intensive Care Society's (ANZICS) 'Statement on Care and Decision-Making at the End of Life for the Critically Ill'. The full chapter titled 'Managing Conflict' (13 pages) covers in detail:

- strategies for dealing with medical consensus
- strategies for dealing with conflict and disagreement with patients and families
- strategies for dealing with a more serious escalation of conflict.

While the ANZICS Statement relates to staff in intensive care units (ICU), many key messages are translatable to other medical and health professional teams. The full Statement is available at: [www.anzics.com.au/Downloads/ANZICS%20Statement%20on%20Care%20and%20Decision-Making%20at%20the%20End%20of%20Life%20for%20the%20Critically%20Ill.pdf](http://www.anzics.com.au/Downloads/ANZICS%20Statement%20on%20Care%20and%20Decision-Making%20at%20the%20End%20of%20Life%20for%20the%20Critically%20Ill.pdf).

Conflict can occur among the intensive care team and other medical teams or between the intensive care team and families. Serious conflict can most often be solved with early, sensitive and proactive communication. Listening and empathising with the concerns of the other party are important steps towards compromise. Unresolved conflict can be damaging to all involved parties.

### Conflict with other medical teams

Professional disagreement with other medical teams can generally be resolved through careful discussion and assessing responses to further treatment. All parties must remain mindful of the prognostic uncertainty in serious illness and accept that genuine clinical disagreement is a healthy part of effective health care. ICU staff should recognise that the burden of treatment, anticipated length of treatment and the level of disability that would occur with survival are important considerations for families and patients. Intensivists should not involve the family in professional disagreements. All medical teams should be made aware of the views of the patient, family and substitute decision-makers.

Mechanisms to resolve ongoing clinical disagreement can include: asking the single dissenting doctor to find a peer who agrees with their position, or obtaining an independent second opinion from a specialist who is uninvolved in the case. Ongoing difficulties should involve escalation to the relevant heads of departments or a clinical ethics committee, if available.

All clinicians must adhere to good medical practice as defined in the relevant codes of practice. This should assist in avoiding conflict in future cases. There should be no tolerance of bad behaviour and reporting of the issue should be escalated immediately to the appropriate level of hospital administration.

### Conflict with families

When there is disagreement with families, regular meetings with consistent personnel are highly desirable to avoid miscommunication and escalation of the disagreement. At all times intensivists should retain a clear focus on the best interests of the patient and be willing to negotiate a compromise.

Common sources of disagreement include:

- Disagreements about prognosis and patient wishes
- Differing views on what represents a successful outcome
- Understanding cultural or religious values
- Family feeling responsible for the death of the patient
- Emotional overlay from previous unsatisfactory interactions between the staff and the patient or family.

Patients and families will often be affronted and resist treatment cessation if the prospect of death is only raised late in the course of an illness. Open and sensitive communication early in the course about the risk of death is needed to ensure that all parties are aware of the possible outcomes. Indicators that families are not able or willing to understand the medical opinion include: circular conversations, requests to read the case notes, avoidance of the medical team, criticising individual members of the hospital team and trying to control the medical decisions. When such behaviour is identified, an active plan should be made to manage it and prevent further escalation.

If the ICU patient's family is experiencing conflict the family should receive appropriate supports. At times the conflict is between different family members and hospital staff can assist with providing clear information and help minimise disruption and damage to relationships. Personal threats to staff should not be tolerated and reporting of the threat should be escalated to an appropriate level immediately.

### **Other options for resolving disagreement**

Resolving a disagreement often requires time and cannot be forced. External second opinions and third party facilitation should not be reserved until the disagreement is intractable. Occasionally patient transfer or a legal solution may be required. If these steps are being considered it is appropriate to seek institutional legal advice.

## Appendix I: Further illustrative case studies

### Element 2: Respecting patient autonomy and supported decision making, and providing personalised care

#### Case study 9: A 75-year-old patient who has had Still's (RA) disease from age four

Mrs Roberts is a 75 year old with multiple joint deformities, serious contractures (knees fixed in ~ 90 degrees flexion, minimal hand function) due to juvenile idiopathic arthritis or Still's disease. She usually lives alone with occasional help, but has been in hospital for four months with multiple joint infections (multi-resistant), ischaemic feet (with dry gangrene of most toes), malnutrition, intrusive pain at multiple sites and inability to eat. After long discussion, she decides to forego further antibiotics and declines vascular surgery review, expecting to die.

Following palliative pain management she feels surprisingly better and she changes her mind, requesting further treatment including joint washouts, 'reserved' antibiotics, etc. After two months she is discharged with ischaemic feet and continues to live alone 12 months later.

#### Reflective considerations

- Always prioritise symptom management – it may alter the patient's attitude to their illness and future, including their acceptable outcome.
- Patients have a right to change their mind.

### Element 3: Ensuring that medical treatment decisions respect the patient's best interests

#### Case study 10: A 74-year-old patient with a large myocardial infarction, with an embolus to his brain causing aphasia and dense hemiplegia

Mr Brown is a 74-year-old previously fit man presenting with a large myocardial infarction, with an embolus to his brain causing aphasia and dense hemiplegia. He was barely rousable, and on the second day he had a further embolus to his left internal iliac artery which was not resectable, resulting in whole leg ischaemia. The surgeons scheduled an amputation as a lifesaving procedure. When his wife and family understood the likely need for a very high amputation and the expected poor outcome, they requested palliation and stayed with him until he died peacefully.

#### Reflective considerations

- It is not always necessary to "do something".
- Always consider the benefits and burdens of any procedure in terms of what is in the patient's best interests and what will deliver an outcome that is acceptable to the patient, not anyone else.
- Part of end-of-life care is being comfortable with clinical uncertainty.

### **Element 3: Ensuring that medical treatment decisions respect the patient's best interests**

#### **Case study 11: A 90-year-old woman with dementia is admitted from home with a hip fracture following a fall**

Mrs Johnson is admitted from home with a hip fracture following a fall. She is 90 years old and has chronic obstructive pulmonary disease and dementia and lives at home with her daughter Jessica and son-in-law Mark. She requires help with all activities of daily living, including transfers and walking, and has had a number of falls in recent months. Mrs Johnson is still able to recognise family members.

She is in pain, unable to weight bear through the hip and has become delirious. The surgeons speak to Mrs Johnson. She isn't aware of why she is in hospital and what is wrong with her. There is uncertainty as to the anticipated benefits of surgery and concerns about the risk of anaesthesia. Mrs Johnson's daughter is very upset that surgery is not being undertaken urgently and feels that the team are being ageist. As her mother's primary carer, she insists that surgery be reconsidered, and suggests that as her mother's Enduring Power of Attorney she can legally ensure this happens and threatens to sue the hospital if surgery isn't undertaken.

Mrs Johnson is reviewed later that day by the orthogeriatric team. She is clearly in pain, delirious and unable to meaningfully engage in any conversations around the risks and benefits of surgery. The team talk to Jessica about the goals of treatment and how these might best be achieved, including non-operative management. There is no existing advance care directive and Jessica and Mark have not previously discussed end-of-life care with Mrs Johnson to help inform decisions.

It is agreed that management of pain is the priority, and although surgery can often help with pain, there are other modalities of treatment which can be tried first. They explain to Jessica that, even with surgery, Mrs Johnson is unlikely to be a candidate for rehabilitation because of her moderate to severe dementia and that she is unlikely to regain any meaningful function following surgery, particularly as she already requires assistance with all basic transfer and mobility skills.

It is agreed by all that a trial of analgesia be tried in the first instance and that, should this fail, then surgery could still be considered as a palliative approach to managing pain. Clear limits of care are agreed, which include antibiotics for infection, but not escalation of care beyond ward level.

The team also discuss decision making with Jessica and explain that Power of Attorney is about financial management and not health and lifestyle choices. However, as Mrs Johnson's daughter and primary carer, Jessica is considered to be Mrs Johnson's substitute decision-maker in the absence of an appointed legal guardian.

Mrs Johnson's chest condition deteriorates shortly after admission to hospital. She is given antibiotics and oxygen as had been agreed, but after further discussion with Jessica, it is agreed to stop active treatment and focus on symptom relief. A discussion is had around end-of-life care including the possibility of caring for Mrs Johnson at home. Given that Mrs Johnson isn't aware of her surrounds

and the rapidity of her decline, it is decided to provide palliation in the hospital environment, and she dies 72 hours after admission to hospital with her daughter by her side.

**Reflective considerations**

- Family recognising that a family member is nearing the end of their life even before the acute event
- Ensuring that care is individualised and based on assessment and discussion with relevant people
- Being aware of the framework for substitute decision making and the difference between Power of Attorney and a legal guardian
- Being aware of alternatives to surgical intervention
- Importance of establishing limits of care

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