



# ANZICS

**Australian and New Zealand Intensive Care Society (ANZICS)**

**ACN 057 619 986**

**ANZICS Statement on  
Care and Decision-Making at the End of Life  
for the Critically Ill**

**Edition 1.0**

**2014**

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ACN 057 619 986

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ISBN 978-1-876980-17-7

Suggested citation:

Australian and New Zealand Intensive Care Society. *ANZICS Statement on Care and Decision-Making at the End of Life for the Critically Ill* (Edition 1.0). Melbourne, ANZICS, 2014.

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## Statement disclaimer

**The Statement is intended to provide a framework for best practice in respect of critically ill patients at the end of life in Australia and New Zealand and provide strong support to intensive care staff involved in the care of these patients and their families.**

This Statement cannot and will not make a decision for you in an individual case. The case studies presented in this document are illustrative only, are provided to assist learning and should not dictate the outcome of similar cases. The case studies do not set legal precedents or benchmarks. All intensivists should be familiar with the laws and practices of their own health organisation and their jurisdiction.

This Statement references a number of documents published by other organisations including professional societies and governments. While we are confident that the Statement is current at the time of publication, the reader should be aware that the other organisations may subsequently update their documents and produce new documents, and that these updates may not be reflected in this Statement.

The End-of-Life Care Working Group will update the Statement from time to time and the current version will always be the version accessed through the ANZICS website [www.anzics.com.au](http://www.anzics.com.au).

Promulgated: ..... 2014

Date of current document: ..... 2014

## Foreword

The first edition, of what was then called the ANZICS Statement on Withholding and Withdrawing Treatment, was a two-page document produced by a small working group and published in 2003. This group was chaired by Dr Colin McArthur and included Drs Tony Bell, Imogen Mitchell, Brad Power, Ray Raper, Carl Scott, Al Vedig and Rob Young. The focus of that Statement was on providing a principled framework to inform and support intensive care staff caring for critically ill patients under circumstances where the burden of intensive treatment (including pain, suffering and loss of dignity) may exceed the potential benefit.

It included recommendations about the processes which should be undertaken under these circumstances, involving the patient and the patient's family, the ICU team and other involved medical teams. It also acknowledged that intensive care services are provided within a broader context of medical services and recommended that guidelines be developed locally which considered 'organisation and legal issues, as well as religious, ethnic, cultural diversity'.

Following preliminary work undertaken by a small group of intensivists in 2010 and 2011, in 2012 the ANZICS Board asked the ANZICS Death and Organ Donation Committee (DODC) to review this Statement and create a more comprehensive document which reflected and supported current practice in the care of critically ill patients at the end of life in Australia and New Zealand. The DODC formed a Working Group consisting of six DODC members together with eight other invited intensivists with particular expertise in these matters.

The Working Group created the current document through meeting face-to-face, by teleconference and by email. An advanced draft was approved by the ANZICS Board and sent for consultation to ANZICS members and external organisations including learned colleges. Fifty-eight submissions were received and are listed in Appendix A. Consultation feedback was reviewed by the Working Group. The feedback was unanimously supportive of the statement with much constructive feedback. A final draft was endorsed by the ANZICS Board in October 2014.

This Statement builds on the 2003 ANZICS Statement, but provides considerable detail on the clinical context, ethical principles and the legal framework in Australia and New Zealand in which critically ill patients and their families are cared for at the end of life. Guidance is given on processes and a limited number of specific recommendations are made regarding good clinical practice.

Considerations pertaining particularly to infants and children are included, along with a number of other special circumstances and specific diagnoses. Clinical case examples are used throughout to illustrate important points and to stimulate consideration and discussion. The length of the Statement reflects a comprehensive document that will be used for educational purposes. The repetition of key points in different chapters is deliberate to ensure that these points are brought to the attention of those readers who only refer to certain sections.

The review of the Statement has occurred at a time of considerable change in medical practice – great medical advances leading to increased survival, resulting in a burgeoning older population, many of whom have chronic disease. As a consequence there is growing professional and public awareness of what cannot be achieved, particularly near the end of life, hence the interest in advance care planning and in improved care at the end of life. This has been reflected in changes in legislation, clinical guidelines, healthcare accreditation requirements and in clinical training and, in

recent years, in landmark Supreme Court declarations. The public interest is palpable through the media and has spurred political attention.

The Statement is intended to provide a framework for best practice in respect of the care of critically ill patients at the end of life in Australia and New Zealand and provide strong support to intensive care staff involved in the care of these patients and their families. The Statement will exist only in an electronic form in order to facilitate access, with links to resources and references, and to enable up-to-date revision by the Working Group to remain consistent with legislative or other changes. The most current version of this working document can be accessed at [www.anzics.com.au](http://www.anzics.com.au). We would appreciate your constructive feedback.

Thank you to all members of the Working Group, the staff of ANZICS, Dr Karen Detering and Professor Ben White and the medical editors of ScribblersInc, in the preparation of this Statement.

Associate Professor William Silvester  
Chair, ANZICS Death and Organ Donation Committee  
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Date of publication: Edition 1.0 2014

Edition 1.0 2014

Proposed review date: 2018

## Principles of end-of-life care

There is more to the art of intensive care than the diagnosis and treatment of critical illness or the application of science and technology.

*The success of intensive care is not, therefore, to be measured only by the statistics of survival, as though each death were a medical failure. It is to be measured by the quality of lives preserved or restored; and by the quality of the dying of those in whose interest it is to die; and by the quality of human relationships involved in each death.*

– G.R Dunstan,<sup>1</sup> University of London, 1984

*... the question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care.*

– Lord Goff of Chieveley,<sup>2</sup> 1993

*If the court is satisfied that the opinions of the doctors have been reached after careful consideration having regard to the correct and relevant matters and are opinions reached in the proper exercise of their professional judgment as to what is in the best interests of their patient, then I very much doubt that a court would ever make an order of the kind sought here. That is because it is not the role of the court to interfere in such a professional relationship and to compel action by an unwilling participant which would have the consequence of placing that individual in the position, in good conscience, of choosing between compliance with a court order and compliance with their professional obligations.*

– Justice Garling,<sup>3</sup> 2012

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<sup>1</sup> GR Dunstan, 'Hard questions in intensive care. A moralist answers questions put to him at a meeting of the Intensive Care Society, Autumn, 1984', *Anaesthesia*, vol. 40, 1985, pp. 479–82.

<sup>2</sup> *Airedale Hospital Trustees v Bland* (1992) UKHL 5 (04 February 1993), <http://www.bailii.org/uk/cases/UKHL/1992/5.html>, accessed 9th April 2014.

<sup>3</sup> *TS & DS v Sydney Children's Hospital Network ('Mohammed's case')* [2012] NSWSC 1609 (24 December 2012), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2012/1609.html>.

## The 10 principles for end-of-life care in intensive care

ANZICS supports the following 10 principles for end-of-life care:

1. The goals of intensive care are to return patients to a quality of survival that is acceptable to them and to reduce disability and, if these are not possible, to compassionately support the dying process. At all times the aim is to minimise suffering.
2. Intensive care treatment is often lifesaving for patients with reversible critical illness. As predicting survival of an individual critically ill patient is imprecise, however, all patients should receive simultaneous attention to both therapeutic (and potentially burdensome) medical interventions and to ensuring their comfort and controlling distressing symptoms.<sup>4</sup> The balance of attention may shift between these objectives during the patient's critical illness, including the possibility that the only objective may be patient comfort and symptom control.
3. When a decision has been made that active treatment is to be withheld or withdrawn, a palliative care plan should be implemented, in consultation with the patient and/or family and the ICU nurse, with a focus on dignity and comfort, considering physical, psychosocial and spiritual needs. The use of medication for patient symptom control in this setting is ethically and legally appropriate, even though this may shorten life.
4. There is no ethical or legal obligation to provide treatments where considered medical opinion is that the burdens to the patient outweigh any potential benefits. The patient and the substitute decision-maker do not have the right to demand treatment (except in Queensland<sup>5</sup>). Medical consensus should be achieved between the intensive care and other medical teams before changing the goals of treatment.
5. The adult patient who has the capacity to decide is entitled to refuse or withdraw consent for any treatment at any time, even if this may shorten his or her life.<sup>6</sup>
6. Medical staff and their patients should aim to make a shared decision about treatment options. The process of shared decision-making involves a consensus among the patient (if the patient has the capacity to make decisions), a substitute decision-maker or family (if the patient does not have the capacity to decide), the intensive care team and other medical teams involved.

Under shared decision-making, the responsibilities of the parties involved are as follows.

It is the responsibility of the intensivist to:

- determine what treatment options are clinically indicated
- determine the existence of an Advance Care Plan or Advance Care Directive if present

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<sup>4</sup> SJ Streat, 'Illness trajectories are also valuable in critical care', *British Medical Journal*, vol. 330, 2005, p. 1272, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC558108/>.

<sup>5</sup> In Queensland, the doctor requires the consent of the patient or substitute decision-maker to withhold or withdraw treatment.

<sup>6</sup> *Brightwater Care Group (Inc) -v- Rossiter* [2009] WASC 229 (20 August 2009), <http://www.austlii.edu.au/cgi-bin/sinodisp/au/cases/wa/WASC/2009/229.html>.

- inform the patient (or substitute decision-maker in the case of a patient who lacks capacity) of the nature (including potential burdens and benefits) of these options and to provide professional recommendations about these options.

It is the responsibility of the patient with capacity to:

- inform the intensivist of what further information they require about the treatment options available in order to be involved in the decision-making.

It is the responsibility of the substitute decision-maker of the patient who lacks capacity to:

- inform the intensivist of the patient's (and their own) goals, values and preferences that will inform decision-making.

It is a shared responsibility of the intensivist, patient or substitute decision-maker to:

- use their shared understanding of the patient's goals, values and preferences, as well as the potential burdens and benefits of the clinically indicated treatment options, to make a decision about what treatments should take place. The goal is to reach a shared decision that reflects the best understanding of the patient's prognosis and of the patient's wishes in the current clinical circumstances.

7. In cases when there is disagreement that cannot be resolved with discussion and time, consideration may be given to involving additional medical opinion, non-medical professional opinion (elders, clerics or spiritual advisers), clinical ethics consultation or legal processes.
8. All decisions regarding the withdrawing or withholding of treatment should be documented in the clinical record. The documentation should include the basis for the decision, identify those with whom it has been agreed and specify the treatments to be withheld or withdrawn.
9. The principles set out above apply equally whether withholding or withdrawing treatment is being considered.
10. Every intensive care unit (ICU) and its hospital should develop and implement guidelines in accordance with these principles. This should include the evaluation of care at the end of life as a quality measure.

## Executive summary

### Care and decision-making at the end of life for the critically ill

#### 1 Good medical practice

In care at the end of life, as in all areas of medical practice, doctors have a duty to act in accordance with principles of good medical practice.

In Australia and New Zealand, codes of conduct encompassing good medical practice are provided by the Medical Board of Australia (on behalf of medical boards of the Australian states and territories),<sup>7</sup> the Australian Medical Council<sup>8</sup> and the Medical Council of New Zealand.<sup>9</sup>

These codes cover all areas of professional behaviour including caring for patients, respecting patients, working in partnership with patients and colleagues, acting honestly and ethically, and accepting the obligation to maintain and improve standards.

#### 2 The ethics of end-of-life care (see Chapter 1)

Codes of medical ethics have, over time, contained the principle that doctors should act in the patient's best interests. This applies in end-of-life care as in all areas of medical practice.

The Hippocratic code<sup>10</sup> for instance, states 'I will prescribe regimens for the good of my patients according to my ability and my judgment and never do harm to anyone.'

A commonly used modern Western ethical framework for medical decision-making<sup>11,12</sup> identifies four basic principles, namely autonomy, beneficence, non-maleficence and justice. In the context of this Statement, 'distributive justice' is the term that will be used. The other types of justice are outside the scope of this Statement. Sometimes, in individual cases, these principles are in conflict and the particular circumstances require that the principles are given different weightings. No individual principle always outweighs the other three principles.

The principle of distributive justice (where health professionals, patient and families share responsibility for fairness and equity in decisions) is important because resources must be used wisely for the benefit of the whole community as well as for individual patients.

#### 3 The patient's best interests

In general, the patient's best interests can be regarded as a summation of the basic principles of beneficence (act to benefit the patient), non-maleficence (avoid harming the patient) and autonomy

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<sup>7</sup> Medical Board of Australia, *Good medical practice: a code of conduct for doctors in Australia*, March 2014, <http://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx>.

<sup>8</sup> Australian Medical Council, *Good medical practice: A code of conduct for doctors in Australia*, July 2009, <http://www.amc.org.au/index.php/about/good-medical-practice>.

<sup>9</sup> Medical Council of New Zealand, *Good medical practice*, April 2013, <https://www.mcnz.org.nz/news-and-publications/good-medical-practice/>.

<sup>10</sup> R Hulkower, 'The history of the Hippocratic Oath: outdated, inauthentic, and yet still relevant', *The Einstein Journal of Biology and Medicine*, vol. 25/26, 2010, pp. 41–44, <http://www.einstein.yu.edu/publications/einstein-journal-biology-medicine/default.aspx?id=29998>.

<sup>11</sup> R Gillon, 'Medical ethics: four principles plus attention to scope', *British Medical Journal*, vol. 309, 1994, pp. 184–88, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2540719/>.

<sup>12</sup> TL Beauchamp & JF Childress, *Principles of biomedical ethics*, 6th edn, Oxford University Press, New York, 2009.

(the patient's right to know and to make decisions about their own health care). Thus, in general terms, a patient's interests will best be served if the doctor acts to benefit the patient and to avoid harming the patient and takes into consideration the patient's wishes, values and goals, given the clinical circumstance.

The principle of autonomy is important, as the patient's perception of what is in their best interests can differ from that of their healthcare professionals. This is not always straightforward because patients will not always want treatments that health professionals believe to be in their best interests. In this situation, a patient with the capacity to decide has the right to choose from, or refuse, the treatments that are available.

Sometimes the patient's best interests will be served if some or all treatment is withheld or withdrawn. On the other hand, patients or their families may sometimes request treatments that health professionals do not believe to be in their best interests or that they are unable to provide. In such a situation, there is no moral or legal obligation (except in Queensland)<sup>13</sup> to provide treatment where considered medical opinion is that the burdens to the patient outweigh any potential benefits.

#### **4 Determining the patient's best interests in end-of-life care**

Intensivists are integral to the end-of-life decision-making in ICU because of their knowledge of the natural history of critical illness, of what is possible or likely to be achieved with ICU treatments and medical investigations or procedures, and of the burdens of disease and treatment.

Sources of information available to assist the intensivist to determine what is in the patient's best interests are:<sup>14</sup>

1. Previously expressed wishes (including Advance Care Plan or Advance Care Directive)
2. Views of a parent, a guardian, a person holding an Enduring Power of Attorney for Health Care, a court-appointed welfare guardian or a substitute decision-maker
3. Views of the family who know and have an interest in the wellbeing of the patient (for a definition of family see Appendix B – Glossary)
4. Considered medical opinion regarding:
  - a. the proposed benefits of carrying out such a treatment and consequences if they do not
  - b. any alternative treatments available
  - c. the risks and burdens associated with the treatments available
  - d. whether the treatment is being carried out to promote the health, wellbeing or wishes of the patient.

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<sup>13</sup> Uniquely within Australia and New Zealand, Queensland law classifies 'withholding and withdrawal of life-sustaining treatment' as 'health care' and the consent of the patient (or substitute decision-maker) must be obtained to legally permit this, even where ongoing treatment is judged to not be in the patient's best interests (and therefore in conflict with the practitioner's common-law duty). See section 2.1.5.

<sup>14</sup> Adapted from Victorian *Guardianship and Administration Act 1986* – sect 38, [http://www.austlii.edu.au/au/legis/vic/consol\\_act/gaaa1986304/s38.html](http://www.austlii.edu.au/au/legis/vic/consol_act/gaaa1986304/s38.html). See also the definition of best interests in Appendix B – Glossary.

The quantity and quality of information from each of these sources will vary with the circumstance of the individual case and the opinions of the different parties involved will sometimes be in conflict.

The patient's best interests are determined by:

- discussion and agreement between the doctor and the patient, if the patient has the capacity to make his or her own healthcare decisions
- consideration of previously expressed wishes in an Advance Care Directive
- discussion with the substitute decision-maker and family of the patient who has lost capacity.

In emergency situations, if the patient's best interests are not known and the information necessary to make considered decisions is lacking, it may be appropriate to institute life-prolonging treatments provisionally while this information is being obtained.

## 5 The legal framework for end-of-life care (see Chapter 2)

Our common law duty as doctors is to take reasonable steps (as other reasonable doctors would) to act in the patient's best interests.<sup>15</sup>

The law in relation to end-of-life care (as for other areas of medical practice) tends to emphasise the principle of autonomy, particularly as it relates to patient's rights. Adults with legal capacity are free to refuse medical treatment even if that refusal places their lives in jeopardy.

For patients with capacity to make their own healthcare decisions, the situation is the same in both Australia and New Zealand, although the exact legal framework is different in the two countries.

There are significant differences between the legal frameworks in Australia and New Zealand when the patient lacks capacity to provide consent to medical treatment.

**In New Zealand**, patients with the capacity to make their own decisions have a number of rights including, but not limited to, the rights to effective communication, to be fully informed, to make an informed choice and give informed consent, to be supported and to complain. These rights have a legislated basis under The Health and Disability Commission Code of Health and Disability Services Consumers' Rights Regulations 1996 (referred to hereafter as 'the Code'), which is a regulation issued under the *Health and Disability Commissioner Act 1994*.

New Zealand legislation describes the limited situations where a person other than the patient is legally entitled to give consent, and prescribes what should happen when no such person is available (which essentially is to act in the patient's best interests, taking into account any known views of the patient and the views of those with an interest in the welfare of the patient). New Zealand law does not include the concept of a substitute decision-maker.

**In Australia**, both common law and legislation in each Australian state and territory supports the right of the patient who lacks capacity to consent to, or decline, the treatment that is on offer. This is ensured through the instruments of an Advance Care Directive and/or a substitute decision-maker. The substitute decision-maker can be legally appointed (for example, enduring power of attorney or enduring guardian) or recognised as the Person Responsible according to a prescribed hierarchy (for

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<sup>15</sup> L Skene, *Law and medical practice: Rights, duties, claims and defences*, 2nd edn, Lexis-Nexis Butterworths, Sydney, 2004.

example, spouse then carer then child, etc.). The rights of the substitute decision-maker to make decisions to refuse treatment vary between states. This is discussed in detail in Chapter 2.

All Australian jurisdictions except NSW have legislation dealing with written, instructional directives. Advance Care Directives or Advance Care Plans (verbal or written) represent the individual's stated wishes and, under most circumstances, must be followed irrespective of the wishes of the family or the doctor.

Withholding and withdrawal of life-sustaining medical therapy is considered lawful and appropriate in circumstances where there is a valid refusal by the patient or where it is in the patient's best interests. A notable exception to this is Queensland where consent must be obtained from the patient or the substitute decision-maker.

In both Australia and New Zealand, euthanasia and 'physician-assisted dying', where a doctor either administers or withholds therapy with the intent of ending or shortening a patient's life, is not lawful under any circumstances.

Intensivists should refrain from using the term 'euthanasia' in end-of-life care discussions and simply describe exactly what actions are taking place (such as withdrawal of ineffective or burdensome treatment and commencement of palliative care).

Because what is lawful in one jurisdiction may be unlawful in another, ANZICS recommends that intensivists familiarise themselves with the relevant laws that apply to their local jurisdiction. Doctors uncertain of the lawfulness of particular aspects of end-of-life care that they are involved in should seek legal advice.

## **6 Advance care planning (see Chapter 3)**

Advance Care Planning (ACP) is a process that enables people to plan and record their health care preferences in case they become ill or injured and are unable to express these wishes. These preferences may include, but are not limited to, end-of-life decisions.

Based on the ethical principle of autonomy (including fully informed consent), on consideration of human dignity, and as is prescribed by legislation in all Australian jurisdictions except NSW, ACP supports people, with the assistance of their families, to reflect upon their condition, their treatment options and likely outcomes, their goals and values. They can then record their preferences for current and future medical treatment that will then guide the family and medical staff in providing appropriate medical treatment that is in the patient's best interests.

ACP also includes choosing, and formally appointing, a substitute decision-maker who will be able to guide medical staff about a person's health care preferences if they are unable to do so at the time.

ACP improves end-of-life care, compliance with expressed preferences and patient and family satisfaction. It reduces anxiety, depression and post-traumatic stress symptoms in surviving family members.<sup>16</sup> The process of ACP ideally results in the completion of an Advance Care Directive, which should be filed prominently in the patient's medical record and accompanied by an appropriate alert in the appropriate hospital electronic record and alert system. Intensivists should be familiar with the principles of ACP and seek, read and comply with expressed preferences to limit treatment.

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<sup>16</sup> KM Detering, AD Hancock, MC Reade & W Silvester, 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial', *BMJ*, vol. 340, 2010, c1345, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2844949/>.

It is best if the ACP discussion commences outside of hospital, in the community (with the GP or in the aged-care home), while the person still has capacity to consider and document their preferences and in the absence of an acute medical crisis. However, ACP can be conducted effectively in hospitals, including in the pre-operative setting. ACP discussions can be held with the family of patients who have lost capacity, such as aged-care residents with dementia.

Goals-of-Care Plans and Resuscitation Plans are doctor-generated documents to guide staff regarding the treatment plan in any emergency and should align with the patient's preferences, as expressed in Advance Care Directives.

## **7 End-of-life care and the intensive care unit (see Chapter 4)**

In general, admission to intensive care should be reserved for patients with reversible disease whose outcome may be improved by the technology and human resources available in ICUs. Other reasons for ICU admission may include a time-limited trial of ICU treatment when the degree of reversibility is unknown, difficult symptom management (including palliative care), addressing family issues and consideration of organ donation.

Consideration must be given to whether the likely outcome is acceptable to the patient and whether the burdens of treatment will outweigh the benefits. Intensivists provide expert advice on the impact of various ICU interventions and make recommendations, but determination of burden versus benefit must involve the patient and the family.

Ensure a shared understanding of the agreed timelines, avoid setting unachievable goals and time limits and consider if and when to change to a palliative care plan. Good documentation is an integral part of the care process.

In considering the admission of patients who are old, frail and/or with significant comorbidity identifying the potential benefits of ICU treatment is a challenge. Prognostic scoring systems are of limited value in predicting outcome in individuals. Consider factors such as the 'Surprise Question'<sup>17</sup> and current level of function.<sup>18</sup> It is appropriate to gather information from other medical teams and from the family. The decision-making should be shared with the other medical teams and the family, rather than a unilateral decision by the intensivist or leaving the burden of the decision with the patient or family. Each family will differ in how much input they wish to have into the shared decision.

## **8 Decision-making in intensive care**

It should be remembered, while administering life-prolonging treatments to the critically ill, that there are two parallel and concurrent aims of ICU treatment:

1. Intensive therapy – to attempt to restore the patient to health and a level of functioning that is acceptable to them
2. Symptom control – to attempt to reduce the burden of suffering caused by the disease or by intensive therapy.

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<sup>17</sup> The 'Surprise Question' – would you be surprised if this patient were to die in the next 12 months?

<sup>18</sup> Such as: greater than 50% of time spent in bed, frequent hospital admissions, deficits in activities of daily living (ADLs), speech and mobility and greater than 10% weight loss over six months.

As time passes and the response to intensive therapies can be assessed and further information becomes available, it will sometimes become evident that death or severe disability is highly likely or that the burden of continuing intensive therapies is greater than the likely benefits. It may then be in the patient's best interests for the balance of ICU treatment to move away from intensive therapy and towards symptom control, dignity and comfort, and not to stand in the way of a natural death, that is, for the aim of treatment to change from prolongation of life to avoidance of suffering and for treatment to be simplified and rationalised accordingly.<sup>19</sup>

When it has been decided that treatment should move from intensive therapy to palliation, the principles of palliative care should be provided, including maintaining comfort and dignity, attending to psychological and spiritual needs, and supporting the family. Staff should be given clear instructions about which treatments are to be continued or withheld.

At times it may be appropriate for the intensivist to participate in end-of-life discussions in the general wards. Particularly out of hours, as a result of the Medical Emergency Team's role, ICU staff can be obliged by default to provide a leadership role in end-of-life discussions in the wards. At times the other medical teams must take responsibility for the discussions with the patient and/or family.

### **9 Consensus building, communication and documentation (see Chapter 5)**

Life-sustaining treatment in Australia and New Zealand may be withdrawn or withheld where treatment is deemed inappropriate in the context of the patient's wishes and their clinical condition. Ideally this is based on a consensus between the patient or their substitute decision-maker, the patient's family, ICU medical team and other medical teams. This is referred to as a shared decision-making process.

Consensus is an opinion or decision reached by a group as a whole, where that decision can be supported by all members of the group even if it is not the most preferred opinion or position of each individual. A decision reached through the consensus of all interested parties is more likely to be a well-considered and appropriate decision and less likely to be subject to complaints or legal review than decisions reached by other methods such as:

- Paternalistic and unilateral decision-making by the responsible doctor.
- Majority vote, which may be adversarial and which does not emphasise the goal of agreement of all participants.
- Identification of a single family member with 'the right to decide' and deferring important decisions to this person.

In general, consensus about the appropriateness of treatment should be achieved between the ICU team and other medical teams before it is sought with the patient, family and substitute decision-makers (for more information, see Chapters 5 and 6).

An important part of achieving consensus with the patient and/or family is excellent communication. Discussions with patients and/or their families about treatment limitation should ideally occur in stages over a period of time and should include ICU nursing staff and, often, the social worker and/or

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<sup>19</sup> DS Davydow, WJ Katon & DF Zatzick, 'Psychiatric morbidity and functional impairments in survivors of burns, traumatic injuries, and ICU stays for other critical illnesses: A review of the literature', *International Review of Psychiatry*, vol. 21, 2009, pp. 531–8, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2857565/>.  
J Cassell, *Life and death in intensive care*, Temple University Press, Philadelphia, 2005.

chaplain. Family meetings should be carefully planned and conducted. Consideration should be given to the need for translators and/or cultural leaders; such people need to be briefed prior to family meetings.

Implicit in 'excellent communication' is taking care with the use of language, including avoiding certain terms (for example, 'do everything' or 'do nothing' or 'futile') and addressing 'the value of the treatment options' rather than 'the value of the person'. The goal of providing comfort to the dying patient should be emphasised.

Thorough documentation of decision-making processes provides transparency and accountability and ensures that health professionals fulfil their professional and legal obligations and are less likely to have the processes questioned. Intensivists should be familiar with any documents related to end-of-life planning and the status of the substitute decision-makers according to local guardianship laws.

## **10 Managing conflict (see Chapter 6)**

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.

### **11 Care of the dying patient, their family and the medical team (see Chapter 7)**

How patients die and how families deal with death varies greatly. Therefore, the palliative care plan should be individualised to the needs of the particular patient and family. The palliative care plan should include both pharmacological and non-pharmacological measures. Pre-prepared sheets can be useful for prescribing palliative care medications. Doses should be individualised for each patient.

Emotional and practical support should be provided to the patient (if conscious) and the family, including the children. There should be a team approach to care involving nursing staff, social workers, pastoral or spiritual leaders as well as medical staff. This should include an explanation of what the dying process might involve such as gasping and noisy breathing. Attention should be paid to optimising the ICU setting in terms of access, privacy, lighting and removal of monitoring devices and unnecessary tubes and infusions.

Signs of distress in an unconscious patient include restlessness, diaphoresis, hypertension, tachycardia, tachypnoea, grimacing or vocalisation. Attention should be paid to anticipating distress caused by withdrawal of respiratory supports. This might involve possible staged de-escalation of respiratory supports and pre-emptive administration of sedative and analgesic medications. Renal

and cardiovascular support (including deactivation of pacemakers/AICDs) do not require a staged de-escalation.

Some patients survive to ICU or hospital discharge in spite of withholding or withdrawing intensive therapies. Medications should be only administered with the intent of relieving distress, not hastening death.

Access to grief and bereavement services should be made available to families. ICU staff should have access to confidential professional support. Regular multidisciplinary case discussions should become integrated into ICU practice. These should be confidential and non-judgemental, the aim being to improve the overall service.

## **12 Special situations and specific diagnoses (see Chapter 8)**

In Australia and New Zealand, the requirement for consent for treatment is waived in an emergency (where the treatment is required immediately to save the patient's life, prevent serious injury or prevent significant pain or distress).

There are some particular situations that may be encountered in intensive care that are worthy of specific comment.

### **Suicide**

Although suicide is not illegal itself, assisting suicide remains a criminal offence in all Australian and New Zealand jurisdictions. After suicide attempts, it is not uncommon for life-sustaining therapy to be withdrawn or withheld (for example, severe hypoxic brain injury after attempted hanging or overdose). The decision on whether therapy is withheld or withdrawn should always be based on what is in the patient's best interests. The severity of mental illness, and its response or lack of response to treatment, is relevant to how aggressively life-sustaining treatments are pursued. Decisions about withholding or withdrawing therapy should be made in conjunction with the substitute decision-maker.

### **Chronic respiratory disease**

Patients with advanced respiratory illnesses, such as chronic obstructive pulmonary disease (COPD), are at risk of acute exacerbations and sudden deterioration that may result in them being admitted to an ICU for mechanical ventilation and other support. Treatment decision-making for these patients is complicated by the unpredictability of their recovery, unawareness of their preference regarding an acceptable outcome (unless there is an Advance Care Directive), their high levels of anxiety, depression and fear of breathlessness.

### **Motor neuron disease**

People with motor neurone disease (MND) usually die from respiratory failure caused by progressive respiratory muscle weakness; they are also at risk of aspiration pneumonia due to bulbar muscle involvement and poor cough. Although many elect for domiciliary non-invasive ventilation, with improved quality of life and survival, most decline invasive ventilation. For the few that are invasively ventilated, the usual reasons are that the cause of the acute respiratory failure was unknown or there was lack of advance care planning prior to an acute deterioration. Success at weaning is less than 50%.

### **13 Infants and children (see Chapter 9)**

Fundamental ethical questions around life-sustaining treatment for infants and children are the same as for older people. One difference is that, for infants and perhaps to a lesser extent older children, we usually do not have evidence of their own views or wishes about treatment. Treatment decisions, made with the child's parents are, therefore, based largely on the ethical principles of beneficence and non-maleficence, and intensivists are morally and legally obliged to always act in a child's best interests.

Occasionally parents and health professionals reach different conclusions about treatment for a child. While parents usually do what they feel is best for their child, it is not always appropriate or necessary to follow parents' requests.

Once it has become apparent that life-sustaining measures are no longer indicated, the focus of efforts is to ensure the provision to the child and their family 'as good a death as possible'.

### **14 Organ and tissue donation (see Chapter 10)**

Organ and tissue donation are an integral part of end-of-life care and should always be considered. All opportunities for organ donation should be recognised and preserved in circumstances where brain death is likely to occur, or where therapy is to be withdrawn and death is expected shortly afterwards. We recommend that the local donor agency should be contacted early, whenever organ or tissue donation is a possibility.

Consult the *ANZICS Statement on Death and Organ Donation* for details of donation after brain death, donation after circulatory death (DCD) and tissue-only donation.

### **15 Evaluating the quality of end-of-life care (see Chapter 11)**

The quality of end-of-life care and long-term morbidity in survivors should be a feature of all ICU Safety and Quality programs.

Intensivists should understand the 12 principles of a good death and recognise that not all can be provided in an ICU environment. These are:

1. To know when death is coming and understand what can be expected
2. To retain control of what happens
3. To be afforded dignity and privacy
4. To have control of pain relief and symptom control
5. To have a choice over where death occurs
6. To have access to information and expertise
7. To have access to hospice care
8. To have access to spiritual and emotional support
9. To have control over who is present
10. To be able to ensure their wishes are respected
11. To have time to say goodbye

12. To be able to leave when it is time to go and not be prolonged indefinitely.

Evaluating the quality of end-of-life care should be structured and integral to ICU practice. A follow-up phone call to the family by someone who has had major involvement with the family can improve bereavement care and guide future practice. It is important to inform the family that such a phone call will be made a few weeks after the patient has died.

## Chapter 1 – The ethics of end-of-life care

### 1.1 Overview

This chapter presents information about:

- the four ethical principles of autonomy, beneficence and non-maleficence and justice, which underpin end-of-life medical decisions
- ethical considerations related to culture and religion
- ethical issues for withholding and withdrawing treatment.

Decision-making for, and conduct of, end-of-life care is a challenge to patients, family and healthcare professionals. One commonly used ethical framework identifies four principles that guide decisions and conversations: autonomy (acting in accord with what the patient wants), beneficence (acting to benefit the patient), non-maleficence (causing no harm to the patient) and distributive justice (paying attention to fairness and equity). This Statement will only discuss distributive justice. Although at one level these principles inform each other, they may be in conflict and this may create robust discussion and uncertainty between intensivists, patients and families. Further complicating the area are cultural and religious issues, which can change the balance between the principles and the way that topics are discussed. The case studies are chosen to illustrate some ways in which culture or religion can influence world views, how that may impact decision-making and the interpretation of advice being given. The understanding of all cultural and religious and indeed personality differences among people is beyond the scope of the Statement.

Some guidance is given regarding these principles. This is discussed below and the associated references suggest other resources offering more information.

### 1.2 The principle of autonomy

The principle of autonomy is the patient's right to both know and choose to make decisions about what happens to their body<sup>20</sup>. It acknowledges that people evaluate options differently and make a range of different choices in their lives. The importance of individual choice and freedom means that patients' choices to refuse should be respected, even if health professionals disagree with them. Autonomy may thus come into conflict with beneficence/non-maleficence.

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<sup>20</sup> 'Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages. This is true except in cases of emergency where the patient is unconscious and where it is necessary to operate before consent can be obtained.' Quote from Justice Cardozo, in *Schloendorff v. Society of New York Hospital*, 211 N.Y. 125, 105 N.E. 92 (1914), in a decision issued by the New York Court of Appeals in 1914. The plaintiff, Mary Schloendorff, was admitted to New York Hospital and consented to being examined under ether to determine if a diagnosed fibroid tumour was malignant, but withheld consent for removal of the tumor. The physician examined the tumour, found it malignant, and then disregarded Schloendorff's wishes and removed the tumour.

**Case example**

A 25-year-old woman sustains major abdominal trauma in a motor vehicle accident. On arrival at the emergency department, she is found to be hypovolaemic and in shock. Fluid resuscitation is commenced and an ultrasound identifies free intraperitoneal fluid and evidence of a ruptured spleen. The woman is conscious and it is explained to her that she will need admission to intensive care and an urgent laparotomy. At this point, the woman explains that she is a Jehovah's Witness and has a religious objection to blood transfusion. She requests that non-blood alternatives be used in the place of transfusion, even if this would put her at risk of complications or death.

**Issues:**

- Capacity to decide and to communicate her decision.
- Absence of coercion.
- Ability to understand the consequences for her.
- Does not need to be a rational choice.

**Resolution:**

- Acknowledge that she does have the right to make this choice.
- If required, seek a second opinion about her capacity to decide.
- Carefully document all advice given.
- Explore her options about blood, blood products, cell-savers and alternatives – there will be a range of decisions that should be individualised.
- Remember that she can make choices but not impose unreasonable demands for treatments that are not available.

Autonomy underlies the importance given to informed consent for medical procedures. Although many patients in intensive care are not able to participate actively in decisions, it is important, where possible, to fully inform patients about treatment and the risks and benefits of available options. For patients who previously had capacity, physicians respect their autonomy by attempting to determine their wishes, goals and values, or by consulting their substitute decision-maker.

Respect for autonomy is treated differently from patient refusal of treatment and demands for medical treatment. Patients with capacity are generally regarded to have an absolute right to decline medical treatment, even if the doctor believes that the treatment would be clearly of benefit. On the other hand, autonomy does not require doctors to provide treatment that they do not believe is medically indicated but the patient demands. This is because a doctor's duty is to always act in the patient's best interests, and because healthcare systems are resource limited and delivering such treatment may have negative effects on the wellbeing of other patients (see section 1.4 for information about distributive justice).

In summary, patients must be given the right to make choices, and sufficient information to make what they believe is the best choice for them. This is captured by the legal notion of 'informed

consent' that has evolved steadily from the 1980s. Where patients cannot decide for themselves, the right devolves to a substitute decision-maker in Australia, and to the treating team in New Zealand. At the same time, doctors (and nurses) are obliged both ethically and as a matter of common law to offer treatments they believe are most beneficial and least harmful. In both jurisdictions there is a commitment to come to a 'shared decision'. In the current climate, conflicting views should be approached with the intent to achieve consensus. This may take time, repeated discussions and external opinions to achieve.

**Case example**

A 73-year-old woman develops sternal osteomyelitis after coronary artery surgery. The sternum is debrided with a latissimus dorsi flap and a tracheostomy is performed. The usual course for these patients in the hospital is a six-week admission, one month in rehabilitation then a return to normal function over a period of months.

The patient has normal capacity and it is explained to her that the most likely outcome is that she will make a full recovery over time. However, she expresses a wish to have the active treatment, including ventilation, withdrawn and a wish to die. Her daughter believes her mother is worried she is will be a burden on her family.

**Issues:**

- Voluntariness (freedom from coercion).
- Capacity to decide.

**Resolution:**

- Exploring the reasons for the patient's wish with the patient and her daughter may uncover factors like sleep deprivation or confusion that could be impairing her capacity to make rational decisions about her future, or factors like disbelief in staff assurances, feelings of personal worthlessness, or misplaced fear of being a burden on others that could be undermining her right to autonomy.

### 1.2.1 Practical suggestions to support patient autonomy

1. Where patients decline medical treatment that would be likely to benefit them, intensivists should first determine if patients have decision-making capacity and, if so, offer all the information required for them to make a decision.
2. Where there is doubt about a patient's capacity to refuse treatment and there is no valid Advance Care Plan, it is recommended that life-sustaining treatment be continued while these issues are clarified.
3. To clarify these issues, intensivists should speak to the substitute decision-maker and/or family and healthcare professionals who have cared for the patient when well, to determine if the patient has consistently expressed a wish regarding treatment options or outcomes.
4. In the circumstance where patients (or their substitute decision-maker) request or demand treatment that would not be considered clinically appropriate, intensivists should attempt to determine the reasons for the patient's request and try to ensure that the patient is fully informed. Intensivists should consult ICU colleagues and it may be advisable to consult other doctors to assess whether they would provide the requested treatment. Intensivists are not required to provide treatment that they do not believe would be of benefit.

### 1.2.2 Guidance regarding the principle of autonomy

Intensivists should consider the following:

- telling (or at least offering to tell) the truth<sup>21</sup>
- looking for and recognising decisions made in advance<sup>22</sup>
- gaining informed consent<sup>23</sup>
- assessing decision-making capacity<sup>24</sup>
- using substituted judgement.<sup>25</sup>

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<sup>21</sup> CH Braddock, *Truth telling and withholding information*, University of Washington, School of Medicine, 2008, <http://depts.washington.edu/bioethx/topics/truth.html>.

Editorial, 'Truth telling in clinical practice', *The Lancet*, vol. 378, 2011, pp. 1197. <http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2811%2961524-9/fulltext>.

<sup>22</sup> The Clinical, Technical and Ethical Principle Committee of the Australian Health Ministers' Advisory Council, *A national framework for advance healthcare directives*, 2011,

[http://www.ahmac.gov.au/cms\\_documents/AdvanceCareDirectives2011.pdf](http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf).

<sup>23</sup> The clinical ethics resource, *Requirement to inform and gain consent – Guidelines and policies*, 2014, <http://clinicaethics.info/consent/requirement-to-inform-and-obtain-consent>.

<sup>24</sup> Attorney General's Department, NSW Government, *Capacity toolkit*, 2008, [http://www.diversityservices.justice.nsw.gov.au/divserv/ds\\_capacity\\_tool.html,c=y](http://www.diversityservices.justice.nsw.gov.au/divserv/ds_capacity_tool.html,c=y).

<sup>25</sup> Victorian Law Reform Commission, *Guardianship: Final report 24, Chapter 17 Responsibilities of substitute decision makers*, 2012, <http://www.lawreform.vic.gov.au/projects/guardianship-final-report>.

Substituted judgement involves a substitute decision-maker (who preferably knows the patient well) seeking to make judgements and decisions that the person would make in the circumstances.

### 1.3 The principles of beneficence and non-maleficence

All medical treatment should be aimed at benefiting the patient and at minimising harm. Beneficence and non-maleficence are thus central to decision-making for both doctors and patients. However, what counts as a benefit or a harm, or how to weigh up different benefits and harms are frequently viewed quite differently by different parties.

#### Case example

A previously well 70-year-old man has an unwitnessed out of hospital cardiac arrest. On arrival of ambulance officers he is found to be in ventricular fibrillation, and has return of spontaneous circulation after approximately 10 minutes of cardiopulmonary resuscitation. He is transferred to hospital and subsequently admitted to the ICU. Over the ensuing days, the man is found to have severe neurological dysfunction with refractory myoclonic seizures. He makes some respiratory effort, but is unable to wean from the ventilator. He has bilaterally absent somato-sensory evoked potentials. Neurology opinion is that he has sustained a profound brain injury and is likely to remain in a persistent vegetative state if he survives. On discussion with his family, it is clear that he has never discussed his wishes with them about medical treatment. His family resist any suggestion that treatment be limited, and ask for a tracheostomy to be performed.

#### Issues:

- The obligation not to harm, and to do good (to act in the best interests of the patient).
- The role of the family in defining what the patient's best interests are in this setting.
- Uncertainty.
- Differences in values and culture.

#### Resolution:

- The discussion should always be based on what is in the patient's best interests, which includes the harms and burdens of ongoing treatment (a substituted judgement), even where this is not known precisely.
- A second medical opinion or clinical treatment ethics committee review can be a useful circuit breaker in circular discussions.
- A wide range of options should be considered if agreement cannot be reached. The courts have an established jurisdiction to resolve intractable conflict, but should not be approached without taking legal advice.
- The family should also be supported to consult with the broader family support network.
- It is likely that a series of meetings, and time for the family to 'see things for themselves', will be required before the family can come to accept the situation.
- It is probable that a court would back a treatment withdrawal decision in this case. However, the approach is one of repeat discussion with a view to gaining consensus.

Sometimes non-maleficence is expressed as ‘primum non-nocere’, or ‘first, do no harm’. But harms and benefits should be considered together. Most intensive treatments involve both risk and suffering, and these risks should be considered in the light of potential benefit.

The burdens or harms of intensive care include many of the inevitable processes that accompany ICU treatment often over a prolonged stay. The procedures are invasive and painful; there is a loss of dignity in front of family and strangers, both physical and at times through delirious behaviour. Friends and family access is often limited, interaction can be difficult, and there is considerable burden on them also, both psychological and managing the disruption to their lives. The uncertainty of the outcome however, can mean that many patients and families endure these burdens without achieving the goal they hoped for, instead, being in a place and having a mode of death far removed from any scenario previously envisaged. Even when survival occurs, considerable physical and psychological sequelae can pervade for many years. Within Australia and New Zealand, around 10% of intensive care admissions, or 12,000 patients, die annually despite admission to ICU. A further 11,000 patients have a level of disability that leaves them requiring discharge to a chronic-care facility.<sup>26</sup>

Despite attention to symptom control, the pain and discomfort is often recollected by survivors of intensive care<sup>27</sup> that contributes to the high levels of post-traumatic stress disorder (PTSD) found in ICU survivors.<sup>28</sup> Distress is not limited to patients, with families of survivors also experiencing high levels of PTSD.<sup>29</sup> Such studies support the common view that dying on intensive care does not provide a good death. (see section 11.2)

Survival is not the only marker of success for intensive care. Having to endure intensive care treatment to survive with severe disability and loss of independence would also be unacceptable to many patients.<sup>30</sup> It remains important that intensivists do not impose their values onto patients or families, but simply explore with them the realities of the potential longer-term outcomes the patient is facing.

The benefits of intensive care are much clearer and the aim is to return patients to a quality of survival that is acceptable to them. Over the last 20 years, standards of intensive care have

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<sup>26</sup> The Australian and New Zealand Intensive Care Society, Centre for Outcome and Resource Evaluation. Annual Report 2012–13, June 2014, [http://www.anzics.com.au/downloads/cat\\_view/4-centre-for-outcome-and-resource-evaluation-core/84-core-annual-reports](http://www.anzics.com.au/downloads/cat_view/4-centre-for-outcome-and-resource-evaluation-core/84-core-annual-reports).

<sup>27</sup> JP van de Leur, CP van der Schans, BG Loef et al., ‘Discomfort and factual recollection in intensive care unit patients’, *Critical Care*, vol. 8, 2004, pp. R467–R473, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1065072/>.

<sup>28</sup> H Myhren, O Ekeberg, K Tøien et al., ‘Posttraumatic stress, anxiety and depression symptoms in patients during the first year post intensive care unit discharge’, *Critical Care*, vol. 14, 2010, p. R14, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2875529/>.

DS Davydow, JM Gifford, SV Desai et al., ‘Posttraumatic stress disorder in general intensive care unit survivors: A systematic review’, *General Hospital Psychiatry*, vol. 30, 2008, pp. 421–434, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2572638/>.

<sup>29</sup> K Sundararajan, M Martin, S Rajagopala & MJ Chapman, ‘Posttraumatic stress disorder in close Relatives of Intensive Care unit patients’ Evaluation (PRICE) study’, *Australian Critical Care*, May 2014, [Epub ahead of print], <http://www.ncbi.nlm.nih.gov/pubmed/24813077>.

<sup>30</sup> TJ Iwashyna, EW Ely, DM Smith & KM Langa, ‘Long-term cognitive impairment and functional disability among survivors of severe sepsis’, *JAMA*, vol. 304, 2010, pp. 1787–1794, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3345288/>.  
S Honeybul, GR Gillett, KM Ho & CR Lind, ‘Neurotrauma and the rule of rescue’, *Journal of Medical Ethics*, vol. 37, 2011, pp. 707–710, <http://jme.bmj.com/content/37/12/707.full>.

continued to rise and mortality has continued to fall.<sup>31</sup> These benefits of intensive care have been seen both bi-nationally and internationally.<sup>32</sup>

For patients who lack capacity, decisions are usually guided by an assessment of their best interests. This is particularly important for patients who have never had capacity, such as adults with an intellectual disability, children and infants (see Chapter 9). Assessing a patient's best interests (see Appendix B – Glossary) includes medical factors such as the patient's apparent prognosis and the likely response to treatment. However, this is complex and the individual patient's response to therapy is uncertain. Recognising and communicating the potential uncertainties in predicting outcomes remains central to communications with patients and families. Added to this are the values of the patient such as their beliefs about life-sustaining treatment, whether they would desire any treatment options that could preserve life and their views about quality of life and the acceptability of surviving in a severely impaired state.

Resolving this requires an in-depth understanding of the potential risks and benefits of a therapy for the individual and an understanding of the patient's (and family's) value systems and goals.

### 1.3.1 Practical suggestions to support beneficence and non-maleficence

1. Where there are different views about what would be in a patient's best interests, try to determine whether these are because of factual differences (about diagnosis or prognosis) or value differences.
2. Where possible, try to determine what values the patient would have applied to the situation at hand given the consequences of ongoing treatment.

### 1.3.2 Guidance regarding the principle of beneficence and non-maleficence

Intensivists should consider the following:

- acting in a patient's best interests<sup>33</sup>
- emergencies<sup>34</sup>
- duty of care<sup>35</sup>
- rule of rescue – a bioethics term that refers to the powerful human tendency to rescue identified endangered lives, regardless of risk or cost. A self-perceived duty or imperative to save life wherever possible, regardless of the consequences, is common among healthcare professionals. The risk may be to the individual being 'saved' (in terms of outcome worse than death).<sup>36</sup> The cost may be at the expense of unidentified endangered lives ('nameless

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<sup>31</sup> The Australian and New Zealand Intensive Care Society, Centre for Outcome and Resource Evaluation. Annual Report 2012–13, June 2014, [http://www.anzics.com.au/downloads/cat\\_view/4-centre-for-outcome-and-resource-evaluation-core/84-core-annual-reports](http://www.anzics.com.au/downloads/cat_view/4-centre-for-outcome-and-resource-evaluation-core/84-core-annual-reports).

<sup>32</sup> JE Zimmerman, AA Kramer & WA Knaus, 'Changes in hospital mortality for United States intensive care unit admissions from 1988 to 2012', *Critical Care*, vol. 17, 2013, p. R81, <http://ccforum.com/content/17/2/R81>.

<sup>33</sup> Medical Protection Society (UK), *Best interests tests*, 2012, <http://www.medicalprotection.org/uk/england-factsheets/MCA-best-interests-test>.

<sup>34</sup> NSW Health, *Consent to medical treatment – patient information*, 2010, [http://www0.health.nsw.gov.au/policies/PD/2005/PD2005\\_406.html](http://www0.health.nsw.gov.au/policies/PD/2005/PD2005_406.html).

<sup>35</sup> RG Beran, 'Duty of care – the need for informed consent', *Legal Medicine Journal*, vol. 3, 2006.

<sup>36</sup> S Honeybul, GR Gillett, KM Ho & CRP Lind, 'Neurotrauma and the rule of rescue', *Journal of Medical Ethics*, vol. 37, 2011, pp. 707–710, <http://jme.bmj.com/content/37/12/707.full>.

faces') who will be denied health care given that the money might be more efficiently spent to prevent deaths in the larger population.<sup>37</sup> The rule of rescue potentially conflicts with the principle of distributive justice.

#### 1.4 The principle of distributive justice

Resources are finite in public health care systems. Careful stewardship and management of these limited resources are central ethical priorities in intensive care. This end-of-life issue, however, is infrequently acknowledged or discussed publicly. Health system charters increasingly include respect for triage decisions in 'patient rights and responsibilities'.

##### Case example

It is winter and the ICU is full. Elective surgery has been cancelled because of a lack of available beds. The intensivist receives a call to notify her that a major high-speed crash has occurred involving a bus and several cars. Multiple casualties are expected in the emergency department, several critically ill. The intensivist initiates discussions with senior nursing staff about existing patients in the ICU. Two patients could be discharged early to the ward to make space, though it had been planned to keep them in the unit. A further patient's extubation could be accelerated and she might be suitable for discharge later. Decisions may still need to be made about which of the trauma patients are admitted to intensive care and which admitted to the ward or transferred elsewhere.

##### Issues:

- Triage in the military sense not used outside declared disaster settings.
- Transparent, reasonable approach.
- Maximising resources.
- Accountability.

##### Resolution:

- If a disaster is not declared, ICU staff are accountable for making reasoned and defensible decisions about the use of ICU resources at this hospital and elsewhere. Minor trade-offs of timing and bed use can be set against providing immediate treatment, but intensive treatment is not so scarce a resource as to justify allowing preventable deaths.
- Provision for existing patients who need ongoing care is mandatory. The public is aware that ICU beds are limited, but rationing of resources is not part of the current debate.
- Disaster, war, epidemics or mass casualties (triage in the military sense) that completely overwhelm resources changes the situation, both in terms of avoiding all preventable deaths and provision of all therapies to existing patients.

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<sup>37</sup> J McKie & J Richardson, 'The rule of rescue', *Social Science & Medicine*, vol. 56, 2003, pp. 2407–2419, <http://www.ncbi.nlm.nih.gov/pubmed/12742604>.

Distributive justice frequently comes into conflict with the principles of autonomy and beneficence. For patients there may be a difference between what they expect for a population and what they expect for themselves. Intensivists experience a conflict between their duty to different patients, within and outside the ICU. The reality is that limited availability of treatment (for example intensive care beds) sometimes means that treatment that is desired or would be of benefit cannot be provided.

Within Australia and New Zealand, the basic principle underlying resource allocation is that healthcare resources should be used to provide the greatest benefit to the greatest number. This is described as a utilitarian, egalitarian approach to distributive justice. Other societies choose different approaches to distributive justice, where a libertarian approach allows patients access to healthcare resources according to their ability to pay. In such systems, it is accepted that access to healthcare is not equal for all.

Ideally, decisions about resource management should be based on clear policies established in advance. Policies should be transparent, relate explicitly to principles that all could accept as relevant, be developed with community input, and include mechanisms for oversight and appeal.<sup>38</sup> However, in practice decisions may need to be made in the absence of clear, relevant, applicable policies.

The options realistically available to the patient and intensivist, within the bounds of the health care system, should form part of the individual discussions. On a broader scale, as the gap between potential and affordable widens, there will need to be increasing community discussion around this topic.

#### **1.4.1 Practical suggestions to support distributive justice**

1. Any decision to decline admission of patients who could potentially benefit from ICU treatment should be made by, or in consultation with, senior intensivists.
2. Wherever possible intensive care should be made available to all patients who are likely to benefit from treatment available only in intensive care. Where ICUs are full this may require transfer to another hospital.
3. Where there is a need to choose between patients, priority should be given to those with the greatest chance (and magnitude) of benefit from intensive care admission, and the highest chance of harm without admission.
4. Triage in the military sense, where the number of casualties exceeds the available resources, is not a feature of intensive care under normal circumstances (see notes above). Health departments use this term to describe allocation of priority, such as is commonplace in the emergency department.

#### **1.4.2 Guidance regarding distributive justice**

Intensivists should consider the following:

- resource allocation – prioritising those who would most benefit

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<sup>38</sup> N Daniels, 'Accountability for reasonableness', *British Medical Journal*, vol. 321, 2000, pp. 1300–1301, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1119050/>.

- reasonableness<sup>39</sup> – the ability to justify the decisions made
- accountability – accepting responsibility for decisions made.

The two concepts of reasonableness and accountability may be combined in the notion of ‘accountability for reasonableness’.<sup>40</sup>

### 1.5 Cultural and religious issues

The balance between the four ethical principles described earlier is also altered by both the intensivist’s and patient’s cultural and religious views, variably encompassing the norms and expectations of the groups with which they associate and identify. Ethical and legal principles have grown with, and are shaped by, the society in which they exist, and thus need to be understood in this context.

#### Case example

A 58-year-old man has presented to hospital after suffering a large intra-cerebral bleed. His condition deteriorates on ICU and he is clinically determined to be brain dead the following morning. He and his family have a strong religious faith. However, they believe that a patient cannot be dead until the heart stops. The family accepts the hopelessness of the situation and that death is inevitable. The death certificate has been completed and gives the time of death as 11.30 am. The intensivist is due to meet the family to discuss the next steps.

#### Issues:

- Respecting the cultural and religious views and values of the family.
- Meeting the legal requirements for declaration of death.
- Maintaining the possibility of organ donation.

#### Resolution:

- Meet with family and have appropriate supports present, including possibly a cultural or religious leader.
- Ensure the family understands that the brain has died and that within Australia and New Zealand this meets the legal definition of death.
- Explain that the intensivist understands that this is not in keeping with the family’s beliefs and accepts that for them death will occur once the heart stops.
- Discuss how the mechanical ventilator would be removed and that shortly afterwards his heart will stop.
- Discuss how, after the heart has stopped, it might be possible for him to be a donor after circulatory death.

<sup>39</sup> N Daniels, ‘Accountability for reasonableness’, *British Medical Journal*, vol. 321, 2000, pp. 1300–1301, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1119050/>.

<sup>40</sup> *ibid.*

Cultural, religious and spiritual views impact significantly on decision-making around the end of life. These views often share similar ethical principles but also have differences in emphasis. Being competent in understanding the views associated with various cultures and religions can help in discussions with families. However, there is often significant variability between individuals within such groups. It is therefore most important that intensivists are sensitive to the views of the individual and which aspects of the religion and culture are important to the patient and their family. It is important to listen to their narrative and perspective, to explore the meaning and implications, and to seek solutions that fit within the framework of the patient and family.

Understanding, interpreting and communicating these views are often difficult for intensivists and patients and their families. Regularly using an individual skilled in religious and cultural interpretation is beneficial, so that all parties involved in these conversations can better understand each other and develop a mutually agreeable treatment plan. For guidance on how to deal with these situations, see Chapters 5 and 6.

### 1.6 Withholding and withdrawing therapy

From an ethical and philosophical perspective there is no difference between withholding and withdrawing treatment. This means that if all other factors are the same, whenever it would be ethical to withhold treatment from a patient, it would also be ethical to withdraw the same treatment if it has already commenced.

Although, this principle has been widely accepted by ethicists as well as in professional guidelines and the law, many medical staff find withdrawing treatment different from withholding.

#### Case example

A 53-year-old man presents to the emergency department with hypoxaemia and respiratory failure. He lives in a residential facility and apparently has a neurological disorder. He is not able to communicate and has no medical records available. No family members are immediately available.

The patient is intubated and admitted to the ICU, where his hypoxaemia improves with modest ventilator settings and intravenous antibiotics.

After admission, it becomes clear that he has a severe neurodegenerative disorder with significant functional decline over recent months. His wife arrives at the hospital and says that, in a number of conversations since his diagnosis, the patient had repeatedly indicated that he would not want intensive life-sustaining treatments provided for him in the event of an acute illness.

The patient is relatively stable on the ventilator and is likely to improve further overnight.

#### Issues:

- Respect for autonomy.
- Agreeing on goals of care.
- Withdrawing treatment in contrast to withholding.

**Resolutions:**

- If it can be established that this patient had expressed a clear wish (even if this is not in written form), then intensivists have an obligation to address this as part of the goals of treatment. All jurisdictions require that the patient's wishes, if known, have a major role in determining best interests when the patient is no longer able to speak for himself.
- When the patient's wish (in this case for palliative treatment) accords reasonably with good medical care there are safe grounds for proceeding to withdrawal of treatment. This is ethically similar to a decision not to initiate treatment in the first place (withholding), though many intensivists feel more comfortable with a decision to withhold. It is important not to over-emphasise the differences between withholding and withdrawing, as trials of treatment, such a crucial part of modern intensive care, would be impossible if the option to subsequently withdraw treatment was not available.
- Withholding or withdrawing treatment is not killing the patient. It is either stopping, or not commencing, artificial treatments that are either not helpful or that intensivists believe will not help. Withholding or withdrawing treatment allows nature to take its course, one way or the other.

One reason that withdrawing treatment appears harder is that people often have a deep feeling that actions are more morally serious than omissions, even if some ethicists disagree with this view. This can also be the case for family members who may be reluctant to agree to stop treatment that has been started. Some religious groups also find stopping treatment harder than not starting.

Another reason can be that the circumstances around withdrawing treatment may be different to withholding. For example, doctors or nurses may have established a personal relationship with the patient in intensive care and be reluctant to 'give up'. Withholding therapy is usually a prospective decision outside of the ICU and the situation may not arise (for example withholding cardiopulmonary resuscitation (CPR)), with the discussion often occurring in a non-intensive care environment, before expectations are set. A time-limited trial of treatment may be the preferred option. In this case, it is best to disclose from the outset the possibility that treatment may be withdrawn if it proves ineffective.

Decisions to withdraw treatment are also more identifiable. There is usually an individual who signs their name in the medical record next to a decision to withdraw treatment and an individual who removes tubing or machines, or turns off infusions. These situations can make practitioners feel more vulnerable and responsible.

Despite the perception that withdrawal is more difficult than withholding, there is some benefit to **withdraw** treatment rather than withhold it. Withdrawing treatment allows assessment of the patient's response to treatment (a therapeutic trial), as well as providing more opportunity to collect additional information about the patient's situation and provide more time for the family to see for themselves that the patient is not going to improve.

**1.6.1 Practical suggestions to support decisions about withholding and withdrawing therapy**

1. If intensivists are unsure whether or not they should withdraw treatment, they should consider asking themselves a different question – 'Knowing what I know now, would I admit this patient to intensive care, or commence treatment with, for example, mechanical

ventilation?’ If the answer is no (that is, treatment would be withheld), consider whether there are valid reasons to treat the decision about withdrawal differently.

2. If a patient’s outlook or their wishes are uncertain, it is better to start treatment, and then subsequently withdraw if the response is insufficient to be beneficial.
3. If a patient or family is reluctant to discontinue treatment, it may be useful to negotiate agreement not to escalate therapy, or to continue treatment for a limited time period with defined expectations for outcomes (for more information about consensus building, see Chapter 5). The emphasis should be on stopping harmful or unpleasant treatments because they are of no benefit.
4. It is sometimes helpful to reframe ‘withdrawing treatment’ in a positive way. For example, withdrawal is not about ‘stopping’ treatment, instead, it is about focusing on treatments that can help rather than those that cannot. In other words, reframe withdrawal as a redirection or refocusing of treatment (for more on language and communication, see Chapter 5).

### 1.6.2 Guidance regarding decisions about withholding and withdrawing therapy

Intensivists should consider the following:

- shared decision-making/consensus building<sup>41</sup> – seeking agreement, or at least assent, from the patient, family and medical team
- family conferences<sup>42</sup> – an essential step in establishing best interests
- burdens and benefits<sup>43</sup> – a broad concept, including medical and non-medical elements but providing a measure by which a treatment may or may not be recommended
- best interests – a measure of benefit over burdens, a term especially used when the patient has not expressed a preference
- substitute decision-making – where another person (usually a family member) makes decisions based on what he believes the patient would have wanted.

At one extreme, life in itself is of infinite value and, at the other extreme, life has value only if it has quality. For those for whom life has infinite value, discussions and agreement about withholding and withdrawing treatment may be difficult.

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<sup>41</sup> NSW Health, *Guidelines for end-of-life care and decision-making*, 2005, [http://www0.health.nsw.gov.au/policies/gl/2005/GL2005\\_057.html](http://www0.health.nsw.gov.au/policies/gl/2005/GL2005_057.html).

<sup>42</sup> JR Curtis, DL Patrick, SE Shannon et al., ‘The family conference as a focus to improve communication about end-of-life care in the intensive care unit: Opportunities for improvement’, *Critical Care Medicine*, vol. 29 (suppl), 2001, pp. N26–N33, [http://journals.lww.com/ccmjournal/Abstract/2001/02001/The\\_family\\_conference\\_as\\_a\\_focus\\_to\\_improve.6.aspx](http://journals.lww.com/ccmjournal/Abstract/2001/02001/The_family_conference_as_a_focus_to_improve.6.aspx).

<sup>43</sup> General Medical Council (UK), *End of life care: Weighing the benefits, burdens and risks*, 2010, [http://www.gmc-uk.org/guidance/ethical\\_guidance/end\\_of\\_life\\_benefits\\_burdens\\_and\\_risks.asp](http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_benefits_burdens_and_risks.asp).

## Chapter 2 – Legal framework for end-of-life care

### 2.1 Overview

This chapter presents information about:

- the court systems in Australia and New Zealand
- responsibilities for end-of-life decisions
- withholding and withdrawal of life-sustaining treatment
- determination of death
- end-of-life decisions in paediatrics.

The Australian and New Zealand legal systems have evolved independently over time from those of the United Kingdom and are based on principles that prioritise autonomy, freedom, equality and respect for the sanctity of human life.

The law in Australia and New Zealand is derived from two sources – the Parliament (statute-based law) and the Courts (case-based or common law). The former refers to Acts of Parliament whereby politicians enact new laws, while common law is based on ‘precedent’. This means that a Court’s decision must be consistent with previous judgements (of equal or higher Courts in the same jurisdiction) around similar issues, or, when a novel issue arises, the Court’s decision sets a precedent. While a judge may be guided or ‘persuaded’ by a decision in a similar case by an equal or higher court in other jurisdictions (including overseas), they are not ‘bound’ to follow such decisions. A basic knowledge of case law around end-of-life issues is therefore relevant to our ICU practice as the principles used in these cases are likely to guide future judgements.

The law is also divided into ‘civil’ and ‘criminal’ law. Basically, civil law is concerned with compensating those who have been wronged. Civil wrongs are often called ‘torts’. Examples of torts include negligence and trespass. Criminal law, on the other hand, is concerned with the protection of society generally, and involves ‘crimes’. Most cases involving end-of-life issues are civil matters with named ‘plaintiffs’ and ‘defendants’ (as opposed to ‘the accused’).

#### 2.1.1 The Australian court system

The structure of the courts in Australia is a federal model consisting of the Commonwealth courts as well as the courts of the states and territories. The High Court sits at the top of both the Commonwealth and state court systems and therefore any decision by the High Court is binding on all ‘lower courts’. (For a diagrammatic overview of the Australian and New Zealand court hierarchies, see Appendix C.) Each jurisdiction has a Coroner’s Court that sits at the Magistrate/District Court level; however, the findings of Coronial Inquiries are not usually open to appeal apart from a few jurisdictions.

In many jurisdictions in Australia, it is usually the state and territory guardianship tribunals that will be asked to intervene in cases involving treatment decisions for patients who lack capacity to ensure that the wishes and interests of the patient are respected. In other jurisdictions, and other

circumstances, it may be the Supreme Court of the state and territory or, in the case of children, the Family Court, which is approached to be involved in end-of-life decision-making.

### **2.1.2 The New Zealand court system**

The New Zealand court system is a single hierarchy comprised of four levels: the District Court (and other specialty courts at the District Court Level, for example, the Coroner's Court), the High Court, the Court of Appeal, and the Supreme Court (the highest court in New Zealand). The High Court has both statutory jurisdiction and inherent common law jurisdiction and tends to hear the more serious jury trials, the more complex civil cases, administrative law cases and appeals from the decisions of courts and tribunals below it (for more detailed information about the New Zealand court system, see Appendix D).

### **2.1.3 The Coroner's Court**

The Coroner's Court operates in all jurisdictions in Australia and New Zealand and is charged with reviewing deaths occurring in specified circumstances ('notifiable' deaths) to establish the cause of death and to ensure that any potential negligent or criminal act is identified and dealt with appropriately. The Coroner has the same status as a Magistrate in Australia or a District Court Judge in New Zealand. The Coroners Act in each jurisdiction outlines which deaths must be referred for review and, depending on the specific circumstances of each death (and legislation in the specific jurisdiction), a Coronial Inquest will be either mandatory or discretionary. The Coronial Process is open to the public. Relatives of the deceased or interested parties are able to attend and present. Although Coroners have no power to act, they can recommend prosecution and can also make broad recommendations to changes to public health and safety practices. It was following Coronial recommendation that Commissioner Garling recently reviewed the entire public acute health care system of New South Wales.<sup>44</sup>

### **2.1.4 Tribunals – New Zealand and Australia**

In addition to courts of law, a number of tribunals exist that are forums primarily for hearing and resolving disputes over facts and/or law concerning administrative matters. Tribunals are usually established and governed by legislation setting out the functions, powers and the extent of its authority, or jurisdiction. The members are often 'subject matter experts', and tribunals are often headed by a legal practitioner rather than a judge. Proceedings tend to be less formal than court proceedings, and rules of evidence are usually less stringently applied.

### **2.1.5 Impacts on intensivists**

Legislation often differs between jurisdictions and it is therefore essential that intensivists familiarise themselves with the relevant laws that apply to their specific situation.

New Zealand has, for example, the *New Zealand Bill of Rights Act 1990*,<sup>45</sup> section 11 of which provides that 'everyone has the right to refuse to undergo any medical treatment'. While Australia

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<sup>44</sup> Commissioner Peter Garling SC, *Final Report of the Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals*, NSW Government, 2008, <http://www.dpc.nsw.gov.au/about/publications>.

<sup>45</sup> *New Zealand Bill of Rights Act 1990*, <http://www.legislation.govt.nz/act/public/1990/0109/latest/whole.html#DLM225509>.

does not have a Bill of Rights (Victoria has a *Charter of Human Rights and Responsibilities Act 2006*<sup>46</sup> and the Australian Capital Territory has a *Human Rights Act 2004*<sup>47</sup>), most Australian states have specific legislation dealing with refusal of medical treatment. This includes the *Medical Treatment Act 1988* (Vic),<sup>48</sup> the *Consent to Medical Treatment and Palliative Care Act 1995* (SA),<sup>49</sup> the *Medical Treatment (Health Directions) Act 2006* (ACT)<sup>50</sup> and the *Powers of Attorney Act 1998* (Qld),<sup>51</sup> *Guardianship and Administration Act 1990* and *Guardianship and Administration Regulations 2005* (WA),<sup>52</sup> the *Powers of Attorney Act* (NT)<sup>53</sup> and the *Powers of Attorney Act 2000* (Tas).<sup>54</sup> Some of these, as well as other useful websites and resources for intensivists, are provided in Appendix G.

Uniquely within Australia and New Zealand, Queensland law classifies ‘withholding and withdrawal of life-sustaining treatment’ as ‘health care’<sup>55</sup> and the consent of the patient (or substitute decision-maker) must be obtained to legally permit this, even where ongoing treatment is judged to not be in the patient’s best interests (and therefore in conflict with the practitioner’s common-law duty).<sup>56</sup>

## 2.2 Making end-of-life decisions

### 2.2.1 The right of patients to make decisions – autonomy and capacity

The law generally respects the rights of individuals to make decisions about their own destiny. Adults (aged more than 18 years) who are considered ‘of sound mind’ (that is, with ‘capacity’) are free to refuse medical treatment even if that refusal places their lives in jeopardy. A medical practitioner who disregards this refusal risks a charge of assault or trespass. It is important to recognise that while the law creates a right to refuse treatment, it does not follow that an individual has the right to demand that intensivists provide treatment they consider to be ‘medically inappropriate’.

A prerequisite for providing ‘informed consent’ is the capacity to understand and critically evaluate the risks and benefits of the proposed treatment options and likely consequences. Intensivists asking patients to make informed decisions also need to be able to assess a person’s capacity to make the decision. The assessment of capacity is specific to the decision the patient is required to make and a detailed exploration of this area is beyond the scope of this chapter. Many variables may affect capacity, including medical condition, medications, pain, and fatigue and psychological issues. The

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<sup>46</sup> *Charter of Human Rights and Responsibilities Act 2006* (Vic), [http://www.austlii.edu.au/au/legis/vic/consol\\_act/cohrara2006433/](http://www.austlii.edu.au/au/legis/vic/consol_act/cohrara2006433/).

<sup>47</sup> *Human Rights Act 2004* (ACT), [http://www.austlii.edu.au/au/legis/act/consol\\_act/hra2004148/](http://www.austlii.edu.au/au/legis/act/consol_act/hra2004148/).

<sup>48</sup> *Medical Treatment Act 1988* (Vic), [http://www.austlii.edu.au/au/legis/vic/consol\\_act/mta1988168/](http://www.austlii.edu.au/au/legis/vic/consol_act/mta1988168/).

<sup>49</sup> *Consent to Medical Treatment and Palliative Care Act 1995* (SA), [http://www.austlii.edu.au/au/legis/sa/consol\\_act/ctmtapca1995420/](http://www.austlii.edu.au/au/legis/sa/consol_act/ctmtapca1995420/).

<sup>50</sup> *Medical Treatment (Health Directions) Act 2006* (ACT), [http://www.austlii.edu.au/au/legis/act/consol\\_act/mtda2006322/](http://www.austlii.edu.au/au/legis/act/consol_act/mtda2006322/).

<sup>51</sup> *Powers of Attorney Act 1998* (Qld), [http://www.austlii.edu.au/au/legis/qld/consol\\_act/poaa1998240/](http://www.austlii.edu.au/au/legis/qld/consol_act/poaa1998240/).

<sup>52</sup> *Guardianship And Administration Act 1990* (WA), [http://www.austlii.edu.au/au/legis/wa/consol\\_act/gaaa1990304/](http://www.austlii.edu.au/au/legis/wa/consol_act/gaaa1990304/), *Guardianship and Administration Regulations 2005* (WA),

[http://www.austlii.edu.au/au/legis/wa/consol\\_reg/gaar2005413/](http://www.austlii.edu.au/au/legis/wa/consol_reg/gaar2005413/).

<sup>53</sup> *Powers of Attorney Act* (NT), [http://www.austlii.edu.au/au/legis/nt/consol\\_act/poaa240/](http://www.austlii.edu.au/au/legis/nt/consol_act/poaa240/).

<sup>54</sup> *Powers of Attorney Act 2000* (Tas.), [http://www.austlii.edu.au/au/legis/tas/consol\\_act/poaa2000240/](http://www.austlii.edu.au/au/legis/tas/consol_act/poaa2000240/).

<sup>55</sup> *Guardianship and Administration Act 2000* (Qld) – Schedule 2, [http://www.austlii.edu.au/au/legis/qld/consol\\_act/gaaa2000304/sch2.html](http://www.austlii.edu.au/au/legis/qld/consol_act/gaaa2000304/sch2.html).

<sup>56</sup> *Guardianship and Administration Act 2000* (Qld) – Sect 79, [http://www.austlii.edu.au/au/legis/qld/consol\\_act/gaaa2000304/s79.html](http://www.austlii.edu.au/au/legis/qld/consol_act/gaaa2000304/s79.html).

Capacity Toolkit<sup>57</sup> may be of assistance. There should be a presumption that patients have capacity to make their own treatment decisions, including refusal of treatment. Where an intensivist judges that a patient lacks the capacity to be involved in decision-making, reasons for coming to such a conclusion must be justifiable and well documented. If intensivists are unsure about the patient's capacity to make decisions, it may be appropriate to consult a psychiatrist.

In some situations, particularly in the ICU, patients may lack capacity to communicate their wishes to the medical team, however, if the patient has a valid Advance Care Directive to refuse treatment, this must be followed. Adults may also appoint a substitute decision-maker to represent their wishes when they are unable to do so. Individuals asked to make decisions based on what they believe the patient would have wanted are called 'substitute decision-makers'. In other circumstances, it is those who are closest to the person in knowledge, care and affection who are asked to decide what treatment should or should not be provided to ensure that the patient receives the care they would have wanted.

Infants and young children are not considered to have ever attained 'capacity' to make medical decisions, and intensivists generally rely on their parents to make decisions on their behalf. In these decisions it is the child's 'best interests' that are paramount.

Adolescents and older children judged to be mature enough to make medical decisions are referred to as 'mature minors' (or 'Gillick competent' minors<sup>58</sup>). However, as alluded to above, 'capacity' is dependent on the nature of the decision to be made. In a number of cases the court has been asked to assess the capacity of children to refuse potentially lifesaving medical treatment, specifically, an adolescent patients' right to refuse blood transfusion in the face of severe life-threatening anaemia on the basis of their religious (Jehovah's Witness) beliefs. The courts have found that, in spite of the adolescent applicants' apparent intelligence and maturity, they may not be considered to have the capacity to refuse potentially lifesaving treatment (see for example, *The Sydney Children's Hospital Network v X* [2013] NSWSC 368).<sup>59</sup> In this situation, at least, the 'best interest' test appeared to trump the principle of 'autonomy'.

### 2.2.2 Substitute decision-makers

Where the patient, for example the intensive care patient, lacks the capacity to make decisions, there are a number of issues around the question of who is the substitute decision-maker for end-of-life decision-making. Under New Zealand law there is no general doctrine of legal consent from relatives to treatment on behalf of an adult who lacks capacity (see Appendix D).

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<sup>57</sup> NSW Government, *Capacity Toolkit*, 2008,

[http://www.diversityservices.justice.nsw.gov.au/divserv/ds\\_capacity\\_tool.html,c=y](http://www.diversityservices.justice.nsw.gov.au/divserv/ds_capacity_tool.html,c=y).

<sup>58</sup> 'Gillick competence' is used for decisions about whether a child (16 years or younger) is able to consent to his or her own medical treatment, without the need for parental permission or knowledge. It is based on a UK House of Lords decision in 1985. The Australian High Court gave approval for the Gillick decision in 'Marion's case' in 1992.

*Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402,

<http://www.bailii.org/uk/cases/UKHL/1985/7.html>.

*Department of Health and Community Services v JWB and SMB (Marion's Case)* [1992] HCA 15; (1992) 175 CLR 218 (6 May 1992), [http://www.austlii.edu.au/au/cases/cth/high\\_ct/175clr218.html](http://www.austlii.edu.au/au/cases/cth/high_ct/175clr218.html).

<sup>59</sup> *The Sydney Children's Hospital Network v X* [2013] NSWSC 368 (28 March 2013),

<http://www.austlii.edu.au/au/cases/nsw/NSWSC/2013/368.html>.

### 2.2.2.1 Guardianship

Much of the legislation relevant to end-of-life care is about ‘guardianship’, in other words, making decisions on behalf of others. There is considerable variation in guardianship law across Australia.<sup>60</sup>

It is important that intensivists become familiar with the guardianship provisions in their own jurisdictions. Note that guardianship appointments can be associated with instructions to the guardian, thus having an overlap with the Advance Care Directive.

The decision-maker for adult patients who lack capacity is often not ‘the senior available next of kin’ but rather follows a specified hierarchy. For example, this hierarchy in New South Wales<sup>61</sup> is, in descending order: the person's appointed guardian; the spouse of the person; a person who has the care of the person; and a close friend or relative of the person. The hierarchy may be different in other jurisdictions, and it is therefore essential that intensivists are familiar with the relevant hierarchy in the jurisdiction they are practising in so they know who can assist with decision-making on behalf of their patient.

This is similar to the situation in New Zealand where the ‘persons entitled to consent on behalf of the consumer’ are specified as: a parent or guardian of a minor; a person holding enduring power of attorney for health care; and a court-appointed welfare guardian. These persons cannot refuse standard treatment intended to save life or prevent serious damage to the patient’s health.

In Australia, guardians appointed by the person do not have the authority to refuse treatment on behalf of the person who lacks capacity. However, court- or tribunal-appointed guardians in all Australian jurisdictions, and Medical Enduring Powers of Attorney appointed by a person in Victoria and Tasmania do have the authority to refuse treatment on behalf of the person who lacks capacity.

In the event that an intensivist wishes to gain consent for medical (or dental) treatment from a Guardian or Guardianship Tribunal (or other agency) on behalf of a person who lacks capacity, the request should generally provide information such as:

- a. the grounds on which it is alleged that the patient is a patient to whom this Part applies
- b. the particular condition of the patient that requires treatment
- c. the alternative courses of treatment that are available in relation to that condition
- d. the general nature and effect of each of those courses of treatment
- e. the nature and degree of the significant risks (if any) associated with each of those courses of treatment
- f. the reasons for which it is proposed that any particular course of treatment should be carried out.

In considering such a request, the substitute decision-maker for the patient must take into account the views (if any) of the patient, as well as the matters referred to above.

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<sup>60</sup> Australian Guardianship Law, *Discovering Australian Guardianship law*, website, <http://www.austguardianshiplaw.org/>.

<sup>61</sup> *Guardianship Act 1987* (NSW), [http://www.austlii.edu.au/au/legis/nsw/consol\\_act/ga1987136/](http://www.austlii.edu.au/au/legis/nsw/consol_act/ga1987136/).

### 2.2.3 Advance Care Directives

Most jurisdictions (with the exception of New Zealand, Tasmania, and New South Wales) have a legislated basis for dealing with written, instructional directives. Advance Care Directives or advance health plans (verbal or written) represent the individual's stated wishes and under most circumstances must be followed irrespective of the wishes of the relatives or, for that matter, intensivists. For more information about Advance Care Directives see Chapter 3.

### 2.2.4 Court jurisdiction over end-of-life decisions

- The Guardianship Tribunal generally has jurisdiction over adults who lack capacity and may be the best tribunal to hear matters involving 'Enduring Guardian' and 'Power of Attorney'.
- The Supreme Court in Australian States and the High Court in New Zealand retain inherent *parens patriae* jurisdiction. This jurisdiction is derived from the right and duty of the Crown as *parens patriae* (parent of the nation) to take care of those who are not able to take care of themselves, including adults who lack capacity and children.
- The Family Court has jurisdiction to decide a range of matters involving 'children of a marriage'. See, for example, a recent Victorian case involving the proposed withdrawal of life-sustaining therapy from an infant, *Baby D*).<sup>62</sup>

As stated earlier, all adults with capacity have the right to refuse medical treatment. In the case of adults who lack capacity, the substitute decision-maker (a previously appointed 'Enduring Guardian' or the 'Person Responsible') may be asked to make decisions regarding what medical treatment an individual may or may not have considered appropriate. When a dispute cannot be resolved between intensivists and patients or their proxies, the case may be referred to either the Guardianship Tribunal or the Supreme Court (High Court in New Zealand) so the courts can decide using their *parens patriae* jurisdiction. This ancient jurisdiction grants rights and responsibility to the Crown to protect the welfare of any vulnerable subjects.

In relation to this power, Justice O'Keefe stated:

*There is undoubted jurisdiction in the Supreme Court of New South Wales to act to protect the right of an unconscious person to receive ordinary reasonable and appropriate (as opposed to extraordinary, excessively burdensome, intrusive or futile) medical treatment, sustenance and support. ... The Court also has jurisdiction to prevent the withdrawal of such treatment, support and sustenance where the withdrawal may put in jeopardy the life, good health or welfare of such unconscious individual. What constitutes appropriate medical treatment in a given case is a medical matter in the first instance. However, where there is doubt or serious dispute in this regard the court has the power to act to protect the life and welfare of the unconscious person.*<sup>63</sup>

A patient's next of kin should be informed that they have the option to involve the Courts if they disagree with the clinicians' decision to withdraw or withhold life-sustaining therapy from their loved one. A Judge of the Supreme Court is 'on-call' in most Australian jurisdictions for emergencies, and once the family has made contact, the Judge will usually then contact the relevant treating clinician to obtain further clinical information as well to determine the urgency of any decision. The Judge

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<sup>62</sup> *Re: Baby D (No. 2)* [2011] FamCA 176 (16 March 2011), <http://www.austlii.edu.au/au/cases/cth/FamCA/2011/176.html>.

<sup>63</sup> *Northridge v Central Sydney Area Health Service* [2000] NSWSC 1241 (29 December 2000), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2000/1241.html>.

may decide to issue interim orders pending a more formal hearing. Some guardianship tribunals may also have mechanisms to be contacted when urgent decision-making is required.

Intensivists should at all times be sensitive to the fears and concerns that patients and their families may have with respect to the decisions intensivists make. To gain insight into a patient's fears around medical end-of-life decisions see the UK case, *Burke, R (on the application of) v General Medical Council & Ors* (2005).<sup>64</sup> Mr Burke expressed concerns about doctors having too much power, including power to make unilateral decisions to withhold or withdraw life support, to determine incapacity, to assess his quality of life, and a general lack of legal scrutiny of the process. His harrowing journey through the legal system included taking on the General Medical Council and an appeal to the European Court.

In the case of children, cases involving end-of-life decisions may be referred to either the Supreme Court as outlined above or the Family Court, because such a case involves 'the welfare of the child of a marriage'. Cases referred to the Family Court have generally tended to be those where there is agreement between the medical teams and child's families on the best treatment, but due to the serious and irreversible nature of the proposed treatment decision, the Family Court may be asked to sanction the decision (see, for example, the case of Baby D).<sup>65</sup>

## 2.3 Withholding and withdrawal of treatment

### 2.3.1 Lawful and unlawful actions

Withholding and withdrawal of life-sustaining medical therapy, including artificial nutrition and hydration, is considered lawful and appropriate in circumstances where there is a valid refusal by the patient and where it is in the patient's best interests. A notable exception to this occurs in Queensland where consent must be obtained as outlined above in section 2.1.5.

In Australia and New Zealand, euthanasia and 'physician-assisted dying', where a clinician either administers or withholds therapy with the intent of ending or shortening a patient's life, is not lawful under any circumstances.

Whether an act or omission is criminal will often depend on the underlying intent. It is recognised that in some circumstances a clinician may administer (act) or withhold (omit) therapy, which has the foreseeable effect of shortening a patient's life although this is not the purpose of the action. However, this is lawful within the widely accepted 'Doctrine of Double Effect' (see section 2.3.2). It remains unlawful to undertake a deliberate act or omission where the **intent** is to shorten a person's life.

### 2.3.2 Defining 'euthanasia' and 'physician-assisted dying'

While best avoided in ICU, as the term is inherently ambiguous, colleagues and families may raise the term 'euthanasia'. Definitions are provided below, as there is much confusion and emotional reaction to the term.

It is not euthanasia to:

- provide appropriate palliative care even if an unintended effect is to hasten death

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<sup>64</sup> *Burke, R (on the application of) v General Medical Council & Ors* [2005] EWCA Civ 1003, <http://www.bailii.org/ew/cases/EWCA/Civ/2005/1003.html>.

<sup>65</sup> *Re: Baby D (No. 2)* [2011] FamCA 176 (16 March 2011), <http://www.austlii.edu.au/au/cases/cth/FamCA/2011/176.html>.

- respect a valid refusal of treatment by a patient with capacity or in an Advance Care Directive
- cease life-sustaining therapy where it is no longer in a patient's best interests.

Intensive care practitioners must never be associated with an act where the *primary intent* is to bring about the death of a patient. Be open about the fact that actions to relieve suffering or provide symptom relief or remove ineffective treatments may have the 'double effect' of an earlier death (see below). This is not 'euthanasia', and death in such circumstances may be seen as a foreseeable but unintended consequence of the act or omission.

Shared decision-making is the preferred model for end-of-life care discussions and there is no place for unilateral decisions by the health care practitioner that the life in discussion is not worth living.

The following three paragraphs are taken from a 'brief' prepared for Members of Parliament in Victoria in regard to the *Medical Treatment (Physician Assisted Dying) Bill 2008* (p. 2–3):<sup>66</sup>

*The word 'euthanasia' is derived from Ancient Greek (combining 'eu' meaning 'good' or 'well' with thanatos meaning 'death' or the 'god of death'). Physician Assisted Dying (PAD) is a relatively new coinage, and is also referred to in some jurisdictions as Physician Assisted Suicide (PAS).*

*Euthanasia has been variously defined, but in the modern context usually concerns the act of ending a person's life in order to relieve the person of pain and suffering. Many commentators identify different forms of euthanasia, making distinctions between 'passive' and 'active' euthanasia, and/or 'voluntary' and 'involuntary' euthanasia. There is no universal agreement on the meanings of these distinctions.*

...

*The doctrine of 'double effect' is a recognised principle of applied ethics. It refers to a principle whereby an action which has a bad effect is defensible provided that: the action itself was good or indifferent; the good effect must be the effect sincerely intended by the agent; the good effect must not be produced by the bad effect; and, there must be a proportionate reason for permitting the bad effect to occur. In the context of care of the dying, a doctor who foresees that as a consequence of administering a treatment to relieve pain that the patient's death may be hastened, he or she is permitted to administer that treatment, if the sincere intention is to alleviate the patient's pain, not to hasten death.*

#### **ANZICS recommendation:**

Intensivists should refrain from using this term 'euthanasia' in end-of-life care discussions and simply describe exactly what actions are taking place (such as withdrawal of mechanical ventilation).

### **2.3.3 Concepts forming the basis of end-of-life decisions**

#### **2.3.3.1 Quality of life**

A number of court decisions have stated that the term 'quality of life' is both a subjective and, potentially, 'pejorative' term and as such it is generally considered unhelpful if disagreement exists. For example, a family might interpret a suggestion that their loved one has a 'poor quality of life' as a

<sup>66</sup> Parliament of Victoria, *Medical Treatment (Physician Assisted Dying) Bill 2008*, <http://www.austlii.edu.au/au/legis/vic/bill/mtadb2008415/>.

failure to take into account the intrinsic value of personhood and a dismissal of their relative's life as 'worthless' or of 'poor quality' (see 'Mohammed's case'<sup>67</sup> and the case of Messiha<sup>68</sup>). The Court has shown a preference instead to balance the potential benefits against the burdens of any proposed treatments or interventions. This approach was adopted in 'Mohammed's case'<sup>69</sup> as well as an English case, *An NHS Trust v MB* (2006).<sup>70</sup>

In Mohammed's case (2012), Justice Garling stated:

*In this case, I think that it is entirely unhelpful to engage in an ill-defined process, which is quintessentially a subjective one for each assessor to determine what Mohammed's quality of life is. I have not made any such assessment and I have disregarded as irrelevant, any expression of opinion by any of the doctors as to what Mohammed's quality of life is or will be.*<sup>71</sup>

### 2.3.3.2 Futility

Honest and open discussions about poor outcomes should be held with the person and/or their family without using the term 'futile'. This should be avoided because:

- it is a highly subjective term which can be used powerfully by doctors and it is hard to refute by the person or family
- it can be influenced by the clinician's own values
- it has negative connotations including the unintended implication that the person, rather than the condition, is not worthwhile, not worth treating and, therefore, 'worthless'
- its meaning is ambiguous and open to misinterpretation.

Using language that describes the treatment as 'not being beneficial', 'over-burdensome' or 'not in the person's best interests' enables clinicians to provide a clear message that the decision is about the effectiveness of the treatment, not the person's worth (see Table 5.1 for recommended language).

*The question is never whether the patient's life is worthwhile but whether the treatment is worthwhile. (Judge Duggan 2003)*<sup>72</sup>

Medical intervention that causes suffering may be acceptable to the person if there is ultimately some benefit to their prognosis or health status, or if it permits them to achieve some other valued goal. However, treatments or investigations that cause suffering to the person should be avoided when there is clearly no benefit to be gained.<sup>73</sup>

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<sup>67</sup> *TS & DS v Sydney Children's Hospital Network ('Mohammed's case')* [2012] NSWSC 1609 (24 December 2012), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2012/1609.html>.

<sup>68</sup> *Isaac Messiha (by his tutor Magdy Messiha) v South East Health* [2004] NSWSC 1061 (11 November 2004), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2004/1061.html>.

<sup>69</sup> *TS & DS v Sydney Children's Hospital Network ('Mohammed's case')* [2012] NSWSC 1609 (24 December 2012), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2012/1609.html>.

<sup>70</sup> *An NHS Trust v MB* [2006] EWHC 507 (Fam), <http://www.bailii.org/ew/cases/EWHC/Fam/2006/507.html>.

<sup>71</sup> *TS & DS v Sydney Children's Hospital Network ('Mohammed's case')* (2012) NSWSC 1609 (24 December 2012), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2012/1609.html>.

<sup>72</sup> Judge Duggan, Vice President of Victorian Civil and Administrative Tribunal, re Tribunal's decision re BWV 2003. BWV [2003] VCAT 121 and Gardner; Re BWV [2003] VSC 173. Judge Duggan made it clear the decision had nothing to do with euthanasia, saying 'The question is never whether a patient's life is worthwhile, but whether the treatment is worthwhile.'

<sup>73</sup> BA Brody & A Halevy, 'Is futility a futile concept?' *Journal of Medical Philosophy*, vol. 20, 1995, pp. 123–44, <http://www.ncbi.nlm.nih.gov/pubmed/7636419>.

The common law on best interests was defined in the landmark Law Lords decision on Anthony Bland, the 18-year-old man who was crushed in the Hillsborough stadium disaster in 1989, causing hypoxic brain damage and leaving him in a persistent vegetative state (post-coma unresponsive state). When his doctor, at the request of the family, contacted the Coroner to indicate his intention to withdraw treatment, the Coroner warned him that he would 'risk a murder charge' He was advised to seek a court direction. The case was heard, appealed and counter-appealed, resulting in an appearance before the House of Lords. The Law Lords allowed the withdrawal of artificial nutrition and hydration. It was stated that 'the treatment imposes a burden not justified by the potential benefits or is not in the patient's best interests'. Lord Goff stated:

*...best interests means that treatment should not be continued simply to prolong life when such treatment has no therapeutic purpose.<sup>74</sup>*

Lord Goff also stated

*But for my part I cannot see that medical treatment is appropriate or requisite simply to prolong a patient's life, when such treatment has no therapeutic purpose of any kind, as where it is futile because the patient is unconscious and there is no prospect of any improvement in his condition. (pp. 863–4)*

and

*[D]iscontinuation of life support is, for present purposes, no different from not initiating life support in the first place. In each case, the doctor is simply allowing his patient to die in the sense that he is desisting from taking a step which might, in certain circumstances, prevent his patient from dying as a result of his pre-existing condition; and as a matter of general principle an omission such as this will not be unlawful unless it constitutes a breach of duty to the patient ...*

*[I]f the justification for treating a patient who lacks the capacity to consent lies in the fact that the treatment is provided in his best interests, it must follow that the treatment may, and indeed ultimately should, be discontinued where it is no longer in his best interests to provide it. (pp. 866–7)*

Lord Goff went on to say that the question was whether on that principle the doctors responsible for the treatment and care of the patient could justifiably discontinue the process of artificial feeding upon which the prolongation of his life depended.

*It is crucial for the understanding of this question that the question itself should be correctly formulated. The question is not whether the doctor should take a course which will kill his patient, or even take a course which has the effect of accelerating his death. The question is whether the doctor should or should not continue to provide his patient with medical treatment or care which, if continued, will prolong his patient's life.*

*The question is sometimes put in striking or emotional terms, which can be misleading. For example, in the case of a life support system, it is sometimes asked: should a doctor be entitled to switch it off, or to pull the plug? And then it is asked: can it be in the best interests of the patient that a doctor should be able to switch the life support system off, when this will inevitably result in the patient's death?*

*Such an approach has rightly been criticised as misleading... This is because the question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care.*

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<sup>74</sup> L Skene, *Law and medical practice: Rights, duties, claims and defences*, 2nd edn, Lexis-Nexis Butterworths, Sydney, 2004.

### 2.3.3.3 Resource pressures

While it might be acknowledged that issues such as pressure on beds (and by extension, resource allocation) are a fact of life, such issues not relevant to the decision as to what represents the patient's best interests. This was specifically mentioned in the case of *Messiha* [at 9] [emphasis added by ANZICS]:

*[T]here was a reference made ...to the availability of the Unit's resources for other patients who were awaiting treatment in the Unit. This was unfortunate because it led to the possibility that the family believed that the decision concerning the future treatment of the patient was, in part at least, being determined by reference to what should, arguably, have been **an irrelevant matter, at least so far as the welfare of the patient was concerned.** If the availability of places in the Unit was raised as a matter to be taken into account ... in determining the future treatment of the patient, it was insensitive to the feelings of the family members and might have been taken as a form of pressure on the family to agree with the hospital's decision.<sup>75</sup>*

And in 'Mohammed's case' [at 64]:<sup>76</sup>

*It was not suggested by the hospital that there was any financial reason, or any reason relating to a shortage of resources, beds or facilities which would preclude Mohammed being provided with mechanical ventilation if that was in his best interests. **There may be occasions when such issues arise. If they do, there are undoubtedly complex questions of public health policy to be considered, and also whether, a Court is best fitted to engage in that area of discourse.** Fortunately, in this case, this issue did not arise.*

#### **ANZICS recommendation:**

The reasons for withholding or withdrawing therapy should be discussed with specific patient-focused language. Therapies that will be given and those that will be withheld should simply be described.

Avoid using the terms 'futile' and 'futility'.

## 2.4 Determination of death

Most jurisdictions (excluding Western Australia and New Zealand) have a statutory definition of death that states:<sup>77</sup>

*For the purposes of the law ... a person has died when there has occurred:*

<sup>75</sup> *Isaac Messiha (by his tutor Magdy Messiha) v South East Health* [2004] NSWSC 1061 (11 November 2004), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2004/1061.html>.

<sup>76</sup> *TS & DS v Sydney Children's Hospital Network ('Mohammed's case')* [2012] NSWSC 1609 (24 December 2012), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2012/1609.html>.

<sup>77</sup> See, for example:

*Transplantation and Anatomy Act 1978* (ACT) – Sect 45,

[http://www.austlii.edu.au/au/legis/act/consol\\_act/taaa1978298/s45.html](http://www.austlii.edu.au/au/legis/act/consol_act/taaa1978298/s45.html).

*Transplantation and Anatomy Act* (NT) – Sect 23, [http://www.austlii.edu.au/au/legis/nt/consol\\_act/taaa298/s23.html](http://www.austlii.edu.au/au/legis/nt/consol_act/taaa298/s23.html).

*Transplantation and Anatomy Act 1979* (Qld) – Sect 45,

[http://www.austlii.edu.au/au/legis/qld/consol\\_act/taaa1979298/s45.html](http://www.austlii.edu.au/au/legis/qld/consol_act/taaa1979298/s45.html).

*Human Tissue Act 1985* (Tas) – Sect 27A, [http://www.austlii.edu.au/au/legis/tas/consol\\_act/hta1985160/s27a.html](http://www.austlii.edu.au/au/legis/tas/consol_act/hta1985160/s27a.html).

*Human Tissue Act 1983* (NSW) – Sect 33, [http://www.austlii.edu.au/au/legis/nsw/consol\\_act/hta1983160/s33.html](http://www.austlii.edu.au/au/legis/nsw/consol_act/hta1983160/s33.html).

*Human Tissue Act 1982* (Vic) – Sect 41, [http://www.austlii.edu.au/au/legis/vic/consol\\_act/hta1982160/s41.html](http://www.austlii.edu.au/au/legis/vic/consol_act/hta1982160/s41.html).

*Death (Definition) Act 1983* (SA) – Sect 2, [http://www.austlii.edu.au/au/legis/sa/consol\\_act/da1983149/s2.html](http://www.austlii.edu.au/au/legis/sa/consol_act/da1983149/s2.html).

- (a) irreversible cessation of all function of the person's brain, or
- (b) irreversible cessation of circulation of blood in the person's body.

Whether or not there is a statutory definition of death, it is the responsibility of the medical practitioner to diagnose death in accordance with good medical practice. The court has no further discretion in the matter once there is 'acceptable and credible evidence' that the patient fulfils the statutory definition of death (see, for example *Krommydas v Sydney West Area Health Service* [2006] NSWSC 901<sup>78</sup>).

Refer to *The ANZICS Statement on Death and Organ Donation Edition 3.2* for further information.<sup>79</sup>

## 2.5 End-of-life decisions in paediatric cases

The best interests of a child include '...the safety, welfare and well-being of the child or young person', and are to be considered paramount in any decisions concerning either the provision or withdrawal of treatment.<sup>80</sup>

Generally, the responsibility for decision-making will rest with the child's parents (or the child if they are considered 'Gillick competent'); however, occasionally a patient may be under the care of the Minister or Director-General or of an appointed Guardian. In such cases, consent for treatment must be sought from the appropriate Person Responsible.

When considering the elements that must be taken into consideration when deciding what course of action would be most appropriate for an infant or child, it is helpful to refer to some of the principles behind the *Children and Young Persons (Care and Protection) Act 1998*, which states:

(1) ...in any action or decision concerning a particular child or young person, the safety, welfare and well-being of the child or young person are paramount.

(2) ...

(a) Wherever a child or young person is able to form his or her own views on a matter concerning his or her safety, welfare and well-being, he or she must be given an opportunity to express those views freely and those views are to be given due weight in accordance with the developmental capacity of the child or young person and the circumstances.

(b) In all actions and decisions made under this Act ...that significantly affect a child or young person, account must be taken of the culture, disability, language, religion and sexuality of the child or young person and, if relevant, those with parental responsibility for the child or young person.<sup>81</sup>

For further reading in this particular area, including the legal aspects, readers are referred to a review<sup>82</sup> and the management of two cases.<sup>83</sup>

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<sup>78</sup> *Krommydas v Sydney West Area Health Service* (2006) NSWSC 901 (18 August 2006), <http://www.austlii.edu.au/au/cases/nsw/NWSC/2006/901.html>.

<sup>79</sup> *The ANZICS Statement on Death and Organ Donation Edition 3.2*, 2013, <http://www.anzics.com.au/death-and-organ-donation>.

<sup>80</sup> *Children and Young Persons (Care and Protection) Act 1998* (NSW) – Sect 9, [http://www.austlii.edu.au/au/legis/nsw/consol\\_act/caypapa1998442/](http://www.austlii.edu.au/au/legis/nsw/consol_act/caypapa1998442/).

<sup>81</sup> *ibid.*

<sup>82</sup> J Tibbals, 'Legal basis for ethical withholding and withdrawing life-sustaining medical treatment from infants and children', *Journal of Paediatrics and Child Health*, vol. 43, 2007, pp. 230–6, <http://onlinelibrary.wiley.com/doi/10.1111/j.1440-1754.2007.01028.x/full>.

In general, a reasoned decision by two or more medical practitioners is likely to be upheld in the Courts. In a number of court cases concerning disagreement between the patient's relatives and the health care providers, the courts have demonstrated a reluctance to enforce treatment orders on the medical staff. This is, of course, provided that it can be demonstrated that the medical opinion has been reached after careful consideration and that it represents a reasonable view.

In 'Mohammad's case', which involved an application to limit invasive ventilation for a young child with a terminal illness, Justice Garling stated [at 93]:

*If the court is satisfied that the opinions of the doctors have been reached after careful consideration having regard to the correct and relevant matters and are opinions reached in the proper exercise of their professional judgment as to what is in the best interests of their patient, then I very much doubt that a court would ever make an order of the kind sought here. That is because it is not the role of the court to interfere in such a professional relationship and to compel action by an unwilling participant which would have the consequence of placing that individual in the position, in good conscience, of choosing between compliance with a court order and compliance with their professional obligations.<sup>84</sup>*

## 2.6 Practical issues for intensivists

### 2.6.1 Will my name be in the press?

While cases involving end-of-life issues have become more common in the courts in Australia and New Zealand, they can still attract media and political attention (for example, Messiha in New South Wales<sup>85</sup> and the Shivo case in the USA). The Court may 'anonymise' the identity of the patient to protect their privacy, and if an intensivist has a justifiable concern that having their name in the public domain may cause them harm, they should highlight this to the Judge who can order that identifying details are suppressed.

The Court process should be seen as 'non-adversarial'. Despite this, many find court experiences stressful, and intensivists should consider approaching their hospital executive, Medical Indemnity organisations or ANZICS to seek appropriate support.

### 2.6.2 What is my legal risk?

Most end-of-life decisions in advance are 'civil' cases, however, a practitioner who acts unlawfully in any way (including 'demonstrating a reckless disregard to human life') can be liable for criminal prosecution attracting either a fine or prison sentence. Fortunately, this is rare and generally reserved for serious criminal negligence.

In circumstances such as the provision of palliative care the medical practitioner, acting in accordance with what is considered to be 'good medical practice', is usually protected from prosecution. However, it is important that intensivists ensure they are familiar with the laws in their own jurisdiction.

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<sup>83</sup> D Isaacs, H Kilham, A Gordon et al., 'Withdrawal of neonatal mechanical ventilation against the parents' wishes', *Journal of Paediatrics and Child Health*, vol. 42, 2006, pp. 311–5, <http://www.ncbi.nlm.nih.gov/pubmed/16712566>.

<sup>84</sup> *TS & DS v Sydney Children's Hospital Network ('Mohammed's case')* [2012] NSWSC 1609 (24 December 2012), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2012/1609.html>.

<sup>85</sup> *Isaac Messiha (by his tutor Magdy Messiha) v South East Health* [2004] NSWSC 1061 (11 November 2004), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2004/1061.html>.

**ANZICS recommendation:**

Intensivists who are uncertain of the lawfulness of particular aspects of end-of-life issues in which they are involved are advised to seek formal legal advice.

Any questions that arise regarding the withdrawal of life-prolonging treatments may also be referred to:

- in Australia, the Coroner, the Health Care Complaints Commission (Australia), the Australian Health Practitioner Registration Authority (Australia)
- in New Zealand, the Medical Council of New Zealand (or State Medical Board), the Health and Disability Commissioner (New Zealand) or other authority for investigation.

Practitioners who have concern about their legal rights or position are advised to contact their Medical Indemnity insurance provider or other legal representative for advice.

**2.6.3 How do I address the Judge?**

Generally, when on the Bench, all Judges of the Supreme Court are addressed as ‘Your Honour’.<sup>86</sup> In conversation, ‘Judge’ should be used unless otherwise indicated. In writing, ‘The Honourable Mr Justice...’ or ‘The Honourable Justice...’. ‘Honourable’ may be abbreviated to ‘Hon.’ and use ‘The Honourable Sir (given name)...’ if knighted. Letters begin ‘Dear Judge,’ unless otherwise indicated.

**2.6.4 How can I access legal cases and legislation?**

For information about legal cases and legislation, intensivists can try the Australasian Legal Information Institute (Austlii),<sup>87</sup> the New Zealand Legal Information Institute (NZLii)<sup>88</sup> and the New Zealand Legislation website.<sup>89</sup> These sites have links to a range of other related online legal databases.

**2.6.5 Where can I go for further help?**

In addition to approaching your hospital’s legal counsel, intensivists seeking further assistance should consider approaching their Medical Indemnity organisations, ANZICS, or the AMA. The guardianship tribunals and adult guardian equivalents may also be able to provide guidance.

**2.7 Mere prolongation of life may not represent the patient's best interests**

There are legal safeguards in place to protect the vulnerable and preserve life in most instances. The law recognises that while the provision of ‘extraordinary’ medical treatment may prolong life, in some instances mere prolongation of life may not represent the patient’s best interests. Any decision to withdraw or withhold such treatment that has clearly been reached in a thoughtful and conscientious manner is likely to be supported by the legal system. Justice Howie stated in the case of *Messiha* [at 28]:

<sup>86</sup> Supreme Court of New South Wales, *Addressing judicial officers*, website, 2013, [http://www.supremecourt.justice.nsw.gov.au/supremecourt/judicialcontacts/addressing\\_judicial\\_officers.html](http://www.supremecourt.justice.nsw.gov.au/supremecourt/judicialcontacts/addressing_judicial_officers.html).

<sup>87</sup> Australasian Legal Information Institute, website, 2014, <http://www.austlii.edu.au/>.

<sup>88</sup> New Zealand Legal Information Institute, website, 2014, <http://www.nzlii.org/>.

<sup>89</sup> New Zealand Government, *New Zealand Legislation* [website], <http://www.legislation.govt.nz/>.

*Apart from extending the patient's life for some relatively brief period, the current treatment is futile. I believe that it is also burdensome and will be intrusive to a degree. ...The Court is in no better position to make a determination of future treatment than are those who are principally under the duty to make such a decision. The withdrawal of treatment may put his life in jeopardy but only to the extent of bringing forward what I believe to be the inevitable in the short term. I am not satisfied that the withdrawal of his present treatment is not in the patient's best interest and welfare.<sup>90</sup>*

**ANZICS recommendation:**

Legislation often differs among jurisdictions and therefore what is lawful in one jurisdiction may be unlawful in another. ANZICS recommends that intensivists ensure they are familiar with the relevant laws that apply to their specific situation.

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<sup>90</sup> *Isaac Messiha (by his tutor Magdy Messiha) v South East Health* [2004] NSWSC 1061 (11 November 2004), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2004/1061.html>.

## Chapter 3 – Advance care planning

### 3.1 Overview

This chapter presents information about:

- advance care planning
- how advance care planning assists patients, families and health professionals in end-of-life decision-making
- practical guidance on advance care planning
- completing Resuscitation Plans.

### 3.2 Advance care planning

Advance Care Planning (ACP) provides people with an opportunity to plan and record their health care preferences in case they become ill or injured and are unable to express these wishes.<sup>91</sup> These preferences may include, but are not limited to, end-of-life decisions.

ACP is based on the right of people to be fully informed about their medical condition on treatment options and to be treated in such a way that respects their dignity and prevents suffering.<sup>92</sup> The process involves health professionals supporting people, with the assistance of their families, to reflect upon their condition, their treatment options and likely outcomes, their goals and values and their preferences for current and future medical treatment.<sup>93</sup> These preferences will then guide the family and medical staff in providing appropriate medical treatment that is in the patient's best interests.

ACP can include choosing, and formally appointing, a substitute decision-maker who will be able to guide medical staff about a person's health care preferences if they are unable to do so at the time. Usually this person is a family member or a close friend and should be someone who would be available if required, can make difficult decisions, and can be trusted to act in the person's best interests and respect their previously expressed wishes.

ACP also gives people the opportunity to record their preferences about specific treatments or document their views regarding unacceptable outcomes in an Advance Care Directive. Then, if they are unable to speak for themselves when the time comes, the Advance Care Directive provides health professionals and substitute decision-makers with important information about the person's desires and, ideally, the underlying reasons.<sup>94</sup>

An Advance Care Directive should be filed prominently in the patient's medical record and accompanied by an appropriate alert in the appropriate hospital electronic record and alert system. It should be sought, found, read and complied with by all hospital doctors who are making treatment decisions on patients who no longer have capacity to make decisions.

<sup>91</sup> <http://advancecareplanning.org.au>

<sup>92</sup> W Silvester & KM Detering, 'Advance care planning and end-of-life care', *Medical Journal of Australia*, vol. 195, 2011, pp. 435–436, <http://www.ncbi.nlm.nih.gov/pubmed/22004382>.

<sup>93</sup> I Scott, G Mitchell, E Reymond & M Daly, 'Clinical focus: Difficult but necessary conversations — the case for advance care planning', *Medical Journal of Australia*, vol. 199, 2013, pp. 662–666, <http://www.ncbi.nlm.nih.gov/pubmed/24237095>.

<sup>94</sup> M Silveira, S Kim & K Langa, 'Advance directives and outcomes of surrogate decision making before death', *New England Journal of Medicine*, vol. 362, 2010, pp. 1211–1218, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2880881/>.

It is best if the ACP discussion commences outside of hospital, in the community (with the GP or in the aged-care home), while the person still has capacity to consider and document their preferences in the absence of an acute medical crisis. This enables individuals, with the support of their families, time to discuss, reflect and identify what is really important to them to 'live well'. 'In the community' means primary care, community health care and residential or home-based aged care.<sup>95</sup> General practitioners (GPs), in whom the person has established trust and confidence, are integral to the commencement of ACP discussions when there is time to help the patient reflect on acceptable outcomes (based on their goals and values) unhampered by acute illness. ACP can be introduced through routine assessments and care planning such as the 75 Plus Health Assessment and Chronic Disease Management planning, or if there is a change in the patient's condition or in routine consultations.

ACP discussions can also be held with the family of patients who have lost capacity, such as aged-care residents with dementia. This enables families, in 'the cool light of day', to make decisions rather than be expected to make stressful and emotionally charged decisions urgently in the middle of the night. Under these conditions families often make uninformed, 'spur of the moment' decisions to 'please do everything' which they frequently regret later.

Models of ACP, such as Respecting Patient Choices<sup>®</sup>, have been developed and these have shown that a coordinated, systematic, patient-centred approach to ACP by trained non-medical facilitators can improve outcomes for patients. This includes ensuring that patients' wishes are known and respected and it has been shown to be sustainable over time. In a recent randomised controlled trial of ACP in inpatients, end-of-life care was improved from both the perspective of the patient and that of the surviving family members and the patient's end-of-life preferences were significantly more likely to be complied with. The patients who received ACP were also more likely to be satisfied with their overall care while in hospital. Furthermore, the ACP reduced the risk of anxiety, depression and post-traumatic stress, in the surviving relatives.<sup>96</sup>

ACP can be conducted effectively in hospitals, including the pre-operative setting. Trials of ACP have also been conducted in the perioperative setting for elderly patients.<sup>97</sup> Song et al. randomised 32 dyads (patient–substitute decision-maker pairs), being seen in a pre-cardiac surgery clinic, to participating in an ACP discussion with a trained nurse for 20–45 minutes.<sup>98</sup> This resulted in greater congruence between the patient and the substitute decision-maker as to what the patient would want if perioperative complications occurred. It also led to the patients, with a mean age of 69 years, experiencing less decisional conflict. The patients reported feeling better informed, more confident in knowing the benefits and burdens of the proposed surgery and feeling less pressure from others as to the decisions to be made.

Grimaldo et al. randomised patients aged 65 years or older and their substitute decision-maker, who were being seen in a preoperative clinic, to a 5- to 10-minute ACP discussion facilitated by an

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<sup>95</sup> W Silvester, RA Parslow, VJ Lewis et al., 'Development and evaluation of an aged care specific Advance Care Plan', *BMJ Supportive & Palliative Care*, vol. 3, 2013, pp. 188–195, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3632978/>.

<sup>96</sup> KM Detering, AD Hancock, MC Reade & W Silvester, 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial', *BMJ*, vol. 340, 2010, c1345, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2844949/>.

<sup>97</sup> W Silvester & K Detering, 'Advance directives, perioperative care and end-of-life planning', *Best Practice & Research Clinical Anaesthesiology*, vol. 25, 2011, pp. 451–460, <http://www.ncbi.nlm.nih.gov/pubmed/21925409>.

<sup>98</sup> MK Song, KT Kirchoff, J Douglas et al., 'A randomized, controlled trial to improve advance care planning among patients undergoing cardiac surgery', *Medical Care*, vol. 43, 2005, pp. 1049–1053, <http://www.ncbi.nlm.nih.gov/pubmed/16166875>.

anaesthetist.<sup>99</sup> This simple intervention significantly increased both the incidence of discussions between the patients and their substitute decision-makers about preferred end-of-life care and the likelihood of the patient appointing a legal decision-maker.

A generic example of an Advance Care Directive (to be completed by the person who has capacity) and an Advance Care Plan (for a substitute decision-maker to complete on behalf of a person who lacks capacity) are shown in Appendix D.

All Australian hospitals are now expected to comply with the National Safety and Quality Health Service Standards, set out in September 2011<sup>100</sup>. The relevant standards are:

- Standard 1.18.4 'Patients and carers are supported to document clear Advance Care Directives and/or treatment-limiting orders'
- Standard 9.8.1 'A system is in place for preparing and/or receiving advance care plans in partnership with patients, families and carers'
- Standards 9.8.2 'Advance care plans and other treatment-limiting orders are documented in the patient clinical record'

**ANZICS recommendation:**

Intensivists seek, identify and comply with a patient's expressed preferences regarding treatment limitation unless there is good reason to believe that the patient's preference would have changed at the time that a treatment decision needs to be made.

**ANZICS recommendation:**

Where appropriate that intensivists assist patients, or substitute decision-makers on behalf of a patient who does not have capacity, to consider and document a patient's preferences regarding limitation of future treatment.

### 3.3 Resuscitation plans

Unlike an Advance Care Directive, which is generated by the patient, a resuscitation plan is completed by a doctor to guide other health professionals if the patient's condition deteriorates rapidly. The purpose of the resuscitation plan is give clear guidance to the ward nursing staff, to avoid inappropriate Medical Emergency Team calls and 'Code Blue' calls and, crucially, to catalyse important discussions between the doctors and the patient/family regarding treatment preferences if this information is not already known. The completion of the resuscitation plan should be guided by, and comply with, the patient's expressed wishes regarding treatment that they do NOT want, as is their common law (and in some jurisdictions, statutory law) right. A generic example of a Resuscitation Plan is shown in the Appendix E.

<sup>99</sup> DA Grimaldo, JP Wiener-Kronish, T Jurson et al., 'A randomized, controlled trial of advance care planning discussions during preoperative evaluations', *Anesthesiology*, vol. 95, 2001, pp. 43–50, [http://journals.lww.com/anesthesiology/Fulltext/2001/07000/A\\_Randomized,\\_Controlled\\_Trial\\_of\\_Advance\\_Care.12.aspx](http://journals.lww.com/anesthesiology/Fulltext/2001/07000/A_Randomized,_Controlled_Trial_of_Advance_Care.12.aspx).  
<sup>100</sup> <http://www.safetyandquality.gov.au/wp-content/uploads/2011/01/NSQHS-Standards-Sept2011.pdf>.

The naming of this document is important. Rather than using a name with a negative connotation, viz Not-For-Resuscitation Form or Do-Not-Resuscitate Form, it is preferable that the name focuses on 'the positive', on what will be done for the patient, hence the 'Resuscitation Plan'. The form can also be referred to as a 'Goals-of-Care' form. A Goals-of-Care form should also include other overall treatment decisions, for example, whether the patient is for further surgery or other interventions in the event of further deterioration.

**ANZICS recommendation:**

Intensivists complete treatment limitation orders in any patient for whom a treatment limitation is in the patient's best interests, or where the treatment limitation complies with the patient's or substitute decision-makers expressed preference regarding a limitation of treatment.

## Chapter 4 – End-of-life care and the intensive care unit

### 4.1 Overview

This chapter presents information about:

- admission criteria for the ICU at the end of life
- palliative care in the ICU
- skills for the ICU team to facilitate appropriate end-of-life discussion and care.

### 4.2 Admission criteria for intensive care

a) In general, admission to intensive care should be reserved for patients with reversible or potentially reversible disease whose outcome may be improved by ICU. When the degree of reversibility is unclear or there is disagreement, it may be reasonable to admit the patient to ICU for an agreed and appropriate period of time to assess response to therapy.

b) Optimal end-of-life care. At times it might be appropriate to admit patients with a low probability of survival in order to manage good end-of-life care.

c) Family management. Problems relating to the family may be present, including a perceived need to allow time for relatives to attend. Be clear, communicate and document these goals to avoid inappropriate expectations from families.

d) Organ donation. Patients with limited or no chance of survival may be admitted to facilitate organ donation. It is important to obtain the family's agreement prior to admission if possible, or to explain and discuss the reason for admission to the family as soon as practicable afterwards.

Important aspects of the assessment of appropriateness of ICU admission are consideration of whether the likely outcome is acceptable to the patient and whether the burdens of treatment will outweigh the benefits. While it is appropriate to provide expert advice on the impact of various ICU interventions and make recommendations, determination of burden versus benefit needs to involve the patient, when possible, and the family.

When admitting to allow time to assess the response to treatment, those sharing the decisions to be made should agree on timelines for reviewing responsiveness to treatment plans. This does not necessitate continuing or escalating treatment until the patient dies. At any time, consider changing to a palliative care plan. Avoid setting unachievable goals and time limits, for example, limiting mechanical ventilation to 24 hours for a severe lobar pneumonia in an elderly patient. This cannot be realistically achieved.

The context of diagnosing the dying ICU patient may be that the death is imminent due to the current condition(s), that is, in hours to days. Imminent death may also be due to, or in addition to, pre-existing advanced incurable conditions. With the ageing population and/or increasing comorbidity, when the request for ICU admission is made, intensivists often see the presence of chronic conditions such as congestive cardiac failure, chronic lung disease, chronic dialysis-dependent renal failure and advanced carcinoma. Defining and getting agreement on the

potential benefits and short-term goals of an ICU admission in these patients is a challenge. It is vital to ensure good documentation in the ICU medical record of:

- the discussion process
- the agreed goals
- any treatment limitations.

The determination of prognosis prior to and during admission is therefore often difficult. Numerical scoring systems have major use in comparing ICUs but are of limited value in predicting outcome when applied to individuals. Determination of prognosis depends on a current detailed clinical assessment and on gathering information from other medical teams, from the literature as well as information about the expert ICU team's experience with the illness and the impact of ICU treatments on life expectancy. These factors are considered in the light of the patient's chronic health condition and the wishes of the patient and family when the burdens and benefits of active treatment are considered. On the one hand, there is no place for unilateral medical decision-making but on the other hand, there is no place for ICU staff offering the patient and family a 'menu' of treatment options that leave the patient and family with the burden of the decision whether to admit or treat in ICU. The doctor should be able to objectively provide the 'best treatment option' or a 'recommended treatment option' to the family and this should also include a 'palliative-only' option.

The ICU team must be careful not to pre-judge or project their own views on the individual's quality of life, particularly in the presence of chronic or degenerative disease. The bottom line is that even after considering all of the above, uncertainty often exists and the quality of care for the patient approaching the end of life must be the same as other ICU patients. The ethical and legal issues that may arise are discussed in Chapters 1 and 2.

### 4.3 Prognosis of chronic organ failure

While age should be no barrier to ICU admission, increasing age brings with it increasing incidence of later-stage chronic disease, increasing general frailty and dementia. The principals of assessing prognosis that are outlined above apply when assessing the impact of a chronic disease on admission to ICU. Like scoring systems for critical illness, scoring systems for prognosticating about co-morbidities apply to a population with a range of possible progressions and uncertainty surrounds applying these to individual patients. It is often combinations of diseases and increasing age and frailty that must be considered. The Royal College of General Practitioners' *GSF Prognostic Indicator Guidance*<sup>101</sup> provides some useful flags of poor prognosis for clinicians:

- Use the 'Surprise Question' when making a summary assessment of survival likelihood by asking, 'Prior to this request for ICU admission, would you have been surprised if this patient were to die in the next six to 12 months?'
- Integrate your knowledge of the comorbidity, social circumstances and place of usual residence (nursing home or other assisted care versus independent living).

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<sup>101</sup> The Gold Standards Framework, *The GSF Prognostic Indicator Guidance*, 4th edn, Royal College of General Practitioners, 2011, <http://www.goldstandardsframework.org.uk/library-tools-amp-resources>.

- Look for such things as greater than 50% of time spent in bed, frequent hospital admissions, deficits in activities of daily living (ADLs), speech and mobility and greater than 10% weight loss over six months.

Indicators such as these, along with disease specific markers, indicate that the patient is in the final stages of the inevitable trajectory to death.

#### 4.4 Case examples

##### Case example

A 75-year-old man is admitted to the respiratory ward with right middle lobe pneumonia. He has been a heavy smoker (40 pack years). He lives with his son who is returning from an overseas business trip and cannot be contacted. It is known that the patient never leaves the house.

On the ward, he becomes increasingly confused and aggressive and he cannot be managed. During a Medical Emergency Team callout, the ICU team are asked to take him to the High Dependency Unit (HDU) for closer monitoring and further management. He is brought down to HDU for some BiPAP, closer monitoring and further investigation. While the patient is having a head CT scan to further investigate his confused state, the son arrives and indicates his father is very limited in his mobility because he is always short of breath.

The CT scan unexpectedly reveals several lesions that suggest secondary cancer. The patient's current clinical condition is such that a decision has to be made with respect to intubation and mechanical ventilation.

##### Issues:

- 'Trial of ICU' – a trial of ICU is appropriate because on the initial request for admission it is not possible to determine how much of this patient's current condition is reversible.
- Difficult symptom management – given nurse patient ratios in the wards, staff will struggle to manage this patient on the ward.
- Integration of knowledge – gathering all the information from the son and investigating results to allow prognostication sets the scene for a family conference to establish whether to escalate ICU care or pursue other goals of treatment.
- The 'Surprise Question'.<sup>102</sup>

##### Resolution:

- It is appropriate to agree to admit the patient to HDU to allow a trial of therapy and to gather more information.
- Integration of information is possible after discussion with the son and once it becomes clear the answer to the surprise question is the patient is likely to die within 12 months. His father, in fact, spends most of the day in bed or watching television on the couch. He noted that his father was becoming increasingly confused at home. The CT scan results are communicated.

<sup>102</sup> Use the 'Surprise Question' when making a summary assessment of survival likelihood by asking yourself, 'Prior to this request for ICU admission, would you have been surprised if this patient were to die in the next six to 12 months?'

- The son agrees that intubation would be inappropriate and is relieved the palliative care team will be involved in his father's care as they were very helpful when his mother developed leukaemia which did not respond to treatment.

### **Case example**

A 60-year-old man with hypertension, type II diabetes, previous myocardial infarction, chronic atrial fibrillation, congestive heart failure and severe chronic renal failure was admitted to the cardiology service with acute pulmonary oedema and a recent 5 kg weight gain. He was alert and cooperative but had respiratory distress and was hypotensive (80/50). Serum potassium was 5.6 and creatinine 640 micromol/L. Chest X-ray showed pulmonary oedema and gross cardiomegaly including left atrial enlargement. He was seen by a cardiologist and given high-flow oxygen by mask, 250 mg of IV furosemide, 5 mg of IV morphine and a dopamine infusion. Twelve hours later, in the middle of the night, he was drowsy, tired, still hypotensive and anuric. The cardiology registrar called a nephrology registrar to suggest dialysis. The nephrology registrar called the ICU registrar and said 'Please admit him to ICU and give him CPAP, a noradrenaline infusion, acute dialysis and fluid removal'.

The ICU registrar assessed him and reviewed his electronic medical record. He had been seen on 18 occasions over the previous two years with progressive renal failure, and had been repeatedly offered dialysis but had refused it. This decision was accepted by his nephrologists who continued to see him regularly at clinic. Reportedly, the nephrology registrar had told the patient that 'You will die tonight unless you are dialysed' and the patient had 'murmured his assent'. The ICU registrar consulted the intensivist on duty.

### **Issues:**

- The patient has presented in crisis after a long period of deterioration during which he refused the offer of chronic dialysis.
- The present situation seems likely to prove fatal with or without intensive care admission.
- Chronic dialysis no longer seems feasible or appropriate in view of his cardiac failure.
- It is not clear if either a cardiologist or a nephrologist has requested ICU admission.

### **Resolution:**

- The intensivist called the nephrologist at home at 0130 hrs. The nephrologist knew the patient well and immediately said 'Surely you haven't been asked to dialyse him have you?'. He decided that acute dialysis should not be offered, because chronic dialysis, which had been indicated and offered before was no longer feasible and would not be offered again.
- After discussion with the cardiologist, the dopamine infusion was stopped. The patient was given small doses of morphine that relieved his respiratory distress and he died six hours later.

**Case example**

A 53-year-old woman presented to the emergency department following a massive haematemesis. She was known to have HCV and previous heavy alcohol intake with cirrhosis, portal hypertension and multifocal hepatocellular carcinoma, and was in the process of being assessed for liver transplantation.

In the ED her oxygen saturation was 85% while breathing high-flow oxygen and she had tachypnea, respiratory distress and shock. Her GCS was 10 (E3, M5, V2). Haemoglobin was 66 g/L, platelets 50, INR 2.2 and fibrinogen 0.5 g/L. She was anaesthetised and ventilated and given blood products and Vitamin K. Endoscopy showed a gastric ulcer with a visibly bleeding vessel that was endoscopically clipped. She was admitted to the ICU and found to have severe aspiration ARDS (F<sub>I</sub>O<sub>2</sub> 0.8, PEEP 14), oliguria and acute kidney injury (serum creatinine 210 micromol/L) and ischaemic hepatitis (AST 2100). Her circulation was hyperdynamic after fluid resuscitation and a noradrenaline infusion at 20 micrograms per minute was required to maintain a MAP of 70 mm Hg, following which her urine output increased to around 60 mL/hr.

**Issues:**

- She has known multifocal HCC but it is yet not known if this exceeds criteria for liver transplantation. This issue can only be clarified after she has recovered from the critical illness.
- Her anticipated ICU mortality is high because of cirrhosis, ARDS, AKI and the risk of further hepatic decompensation and progressive encephalopathy.
- The appropriate intensity and duration of intensive therapies will depend on her clinical course, which is presently uncertain.

**Resolution:**

- The intensivists and the liver transplant service agree to a short trial of intensive treatment (ventilatory support, fluid therapy, inotrope infusion, enteral feeding and measures to reduce encephalopathy, but not renal replacement therapy).
- Over the next three days polyuria develops and renal and respiratory functions improve. She maintains a MAP of 80 without inotropic support, AST falls to 200 and INR stabilises at 1.8 but she becomes increasingly jaundiced and encephalopathic despite lactulose, rifaximin and regular enemas.
- Three days after that she remains deeply encephalopathic (E1, M2) but other organ functions continue to improve. A CT scan shows no intracranial bleeding or brain oedema. It is decided that current therapies will be continued but will not be further escalated.
- After another three days later she has spontaneous eye opening and obeys commands. She is able to be extubated and is transferred to the liver transplant service for ongoing assessment.

#### 4.5 Other medical teams

The views of the other medical teams should not only be considered and respected but team members should be encouraged to attend end-of-life conferences. They bring different expertise and experience to the ICU team and often have a longstanding relationship with the patient. It is hoped that with increasing frequency, they will have already broached the subject of death, particularly in chronic diseases such as dialysis-dependent renal failure, chronic lung disease with home oxygen dependency, congestive cardiac failure and advanced cancer. The ICU team should confer with the other medical teams before the conference and explore the treatment options and the benefits and the burdens and risks of each. For more information about achieving medical consensus, see section 6.2.1.

#### 4.6 Delivering palliative care in the intensive care unit

When it is decided that the focus of ICU treatment should move from treatment to palliation, efforts should be made to see that the major principles of palliative care<sup>103</sup> are provided including maintaining comfort and dignity and giving major attention to psychological and spiritual needs as well as support to the family. ICU staff should be able to provide basic symptom management and in more complex cases a specialist palliative care referral may be valuable, particularly if transfer of the dying patient to the general ward is anticipated.

Clearly written instructions as to what treatment is to be continued, or withheld, should be given. As a general principle, any painful procedures, or investigations that are not likely to alter outcome, should be withheld. Consideration should be given to unrestricted visiting and where possible, providing a single room for the patient and family. Staff who have been involved in the decision-making process should be encouraged to visit the family and patient during the period when the patient is dying. Support from religious or ethnic advisers should be offered where appropriate.

Family members will often ask whether they should stay or go and they should be encouraged to discuss this among themselves, and to understand that the same thing may not be right for individuals. A further common question is whether children should be brought in to farewell a dying relative. In these circumstances, we suggest that children be asked what they want to do, and if they wish to visit, carefully explain to them what they will see. Mention the 'machines that go beep'. Follow up with a 'debrief' chat to explore their reactions and answer any questions that arise from their experience in ICU. The presence of a close family member and the ICU medical social work and/or pastoral care staff throughout is helpful.

After death, appropriate social work support should be given to assist with funeral arrangements, and family should be made aware that they may and should return if they have any problems or unanswered questions. Medical social work and ICU nursing staff can assist the family in any care of the body after death. This includes removal of all ICU equipment when a coronial investigation is not a consideration, thus allowing for a 'more natural' viewing of the body. Offering handprints and collection of a lock of hair may provide comfort to the family.

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<sup>103</sup> World Health Organization, *WHO definition of palliative care*, 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual,' <http://www.who.int/cancer/palliative/definition/en/>.

Special consideration needs to be given to the differing cultural needs of families and their practices around dying. Even in the ICU environment, it is possible to bring their religious and cultural rituals to their dying family member.

Care of the dying patient is covered in more detail in Chapter 7.

#### **4.6.1 End-of-life discussions outside of the intensive care unit**

The question of whether intensivists should lead, participate in or avoid involvement in end-of-life discussions in the general wards is common. Each situation is different. Particularly out of hours, ICU staff can be obliged to provide a leadership role in end-of-life discussions. Intensivists should consider the needs of the other practitioners in their hospital. Senior medical and surgical colleagues may welcome some guidance and assistance in end-of-life care. It may be that this care is best provided in the ward. Irrespective of the role intensivists adopt, the discussion should be collaborative. Encouraging other medical teams to take a leadership role in discussions and early establishment of Advance Care Plans is desirable and hospitals should have policies pertaining to this.

Non-ICU doctors should, ideally, complete a resuscitation plan on any patient for whom a limitation of treatment is appropriate. Completion of a Resuscitation Plan (see template in Appendix E) should be considered in any patient where there is a risk of Medical Emergency Team (MET) call or a Code Blue. This could include patients older than 75 years and patients with advanced cancer, dementia, heart failure or chronic obstructive pulmonary disease (COPD). The completion of a resuscitation plan does not automatically mean that treatment is limited; a patient may be for full resuscitation. Resuscitation plans are discussed further in Chapter 3.

#### **4.6.2 Role of the Medical Emergency Team**

ICU staff often form the Medical Emergency Team (MET). This moves the role of the ICU medical staff out of ICU and into the wards. Several publications indicate that end-of-life discussions, such as instituting a not-for-resuscitation order, can form up to 30% of the work of the MET. This could indicate a failure of prior planning and usually means that the intensivist who assesses whether to admit a patient to ICU is at a trainee level. Gathering the information to inform this decision often takes time and out-of-hours work and can keep the only intensivist out of the ICU for prolonged periods. Ideally the end-of-life discussion should not be rushed or undertaken with incomplete information.

### **4.7 Skills to help the ICU team deliver care at the end of life**

Care at the end of life in the ICU environment is definitely a team effort in order to provide a 'good death' in such an intrusive, noisy and complex setting. Requisite skills are:

- assessment and diagnosis of the dying patient
- pain and symptom relief
- management of anxiety and fear
- good communication for discussions with the patient and/or their family about prognosis, goals of treatment, relief of suffering and likely course of changing from an active resuscitation pathway to palliation.

It is important to involve the bedside nurse in discussions. Nursing staff have a key role in ensuring continuity of these shared goals because they are in constant attendance while medical teams come and go.

Trainees should receive formal training by firstly observing end-of-life discussions, followed by leading the discussions in a supervised environment and finally by running the discussions when supervisors are confident in their ability.

**ANZICS recommendation:**

All ICU staff should obtain expertise in:

- effective symptom control in the dying ICU patient
- communicating effectively with dying patients and their families, and with other health professionals who may also be involved in the care of those persons.

## Chapter 5 – Consensus building, communication and documentation

### 5.1 Overview

This chapter presents information about:

- planning and conducting an effective family meeting
- consensus building and communicating end-of-life concepts
- using interpreters and cultural leaders for end-of-life discussions
- managing meetings with families and interpreters
- documenting processes once consensus is achieved.

Life-sustaining treatment in Australia and New Zealand may be withdrawn or withheld where treatment is deemed inappropriate in the context of the patient's wishes and their clinical condition. Ideally this is based on a consensus among the patient or their substitute decision-maker, other medical teams and the patient's family. This is referred to as a shared decision-making process.

Consensus is defined as an opinion or decision reached by a group as a whole, where that decision can be supported by all members of the group even if it is not the most preferred opinion or position of each individual.

Discussions with patients and/or their families about end-of-life management and treatment limitation can be difficult. Careful use of language can help to reduce distress associated with these discussions and help to build consensus when developing an end-of-life management plan.

When doctors or members of other medical teams are communicating with patients or families where English is not the first language or where cultural concerns are poorly understood, subtle changes of meaning can appear in discussions during translation.

Careful use of translators and management of meetings is advised in these situations. The nuances of language can also trouble doctors for whom English is not the first language. This should be taken into account when deciding who might be the most appropriate clinician to speak to the family.

### 5.2 The role of the clinician

It is the responsibility of other medical teams to determine which treatment options are clinically indicated (treatments that are not indicated should not be offered), and to recommend a plan that they believe is most appropriate while taking into account the known wishes of the patient.

Clinicians need to respect the fact that each patient and family differ in how much influence they wish to have into decision-making. Some families and patients want significant input, while others prefer that decisions are left to the clinicians.<sup>104</sup>

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<sup>104</sup> E Azoulay, F Pochard, S Chevret et al., 'Half of the family members of intensive care unit patients do not want to share in the decision making process: a study in 78 French intensive care units', *Critical Care Medicine*, vol. 32, 2004, pp. 1832–38, <http://www.ncbi.nlm.nih.gov/pubmed/15343009>.

DK Heyland, K Tranmer, CJ O'Callaghan, A Gafni, 'The seriously ill hospitalized patient: preferred role in end-of-life decision-making?' *Journal of Critical Care*, vol. 18, 2003, pp. 3–10, <http://www.ncbi.nlm.nih.gov/pubmed/12640606>.

Families involved in end-of-life decisions, can experience long-term psychological harm.<sup>105</sup> It is important that families are not made to feel an unwanted burden or responsibility for decisions made at the end of life. Careful use of language can help to limit the feeling of personal responsibility associated with these discussions and consensus shares this burden.

**ANZICS recommendation:**

Intensivists should take a leadership role in end-of-life discussions within the ICU. This involves being inclusive and potentially flexible around decision-making at the end of life.

### 5.3 Consensus building

The decision-making process in the end-of-life care in Australia and New Zealand is fundamentally a shared-care model where the health care providers and the family work to try to achieve a consensus agreement for a treatment plan that addresses the patient's wishes (as best they can be determined) and clinical circumstances.

#### 5.3.1 Building medical consensus

Relationships between intensive care and other medical teams are important and need to be constructive. Although many members of the team will communicate at different levels, intensivist-to-consultant contact will help develop the most productive relationships.

For each individual patient, consensus should be built over the course of a patient's stay. Regular updates and discussions on bedside rounds will help to build consensus with those other medical teams who share responsibility for patient care.

It is useful to consider how much influence each specialist should reasonably have when seeking to reach a consensus. For more information about managing conflict between healthcare professionals, see section 6.2.1.

#### 5.3.2 Building consensus with patients and families

It is unusual for patients to be able to participate in end-of-life decisions while in intensive care. On the occasions when they are able to do so, it is important to be confident that they have capacity to do so. Medication, illness, delirium, dependency and dementia can all impair decision-making.

Formal assessment of capacity is important in day-to-day clinical practice to assess a person's ability to participate in decision-making. It should be appreciated that capacity applies to the particular

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GS Chung, RE Lawrence, FA Curlin, V Arora, DO Meltzer, 'Predictors of hospitalised patients' preferences for physician directed medical decision-making,' *Journal of Medical Ethics*, 38, 2012, pp. 77–82, <http://www.ncbi.nlm.nih.gov/pubmed/21697296>.

<sup>105</sup> E Azoulay, F Pochard, N Kentish-Barnes et al., 'Risk of post-traumatic stress symptoms in family members of intensive care unit patients', *American Journal of Respiratory Critical Care Medicine*, vol. 171, 2005, pp. 987–94, <http://www.ncbi.nlm.nih.gov/pubmed/15665319>.

D Wendler & A Rid, 'Systematic review: the effect of surrogates on making treatment decisions for others', *Annals of Internal Medicine*, vol. 154, 2011, pp. 336–46, <http://www.atsjournals.org/doi/full/10.1164/rccm.200409-1295OC-.VFBQudbypZo>.

decision under consideration. Consequently, someone may be deemed to have impaired capacity for some decisions and still have capacity for other decisions where the concepts may be simpler.

For a person to have capacity to make a particular decision, intensivists should assess whether the patient:

- is able to understand the facts and the choices involved for that decision
- is able to weigh up the consequences
- has the capacity to communicate his or her decision.

It is important that the evidence supporting these steps is documented in the medical record (see section 5.7).

**ANZICS recommendation:**

All intensivists should be able to assess a patient's capacity.

Family agreement is best achieved when the family are helped to arrive at a conclusion for themselves (as a result of discussion), rather than being confronted by a predetermined medical decision that they are expected to accept.

In an emergency, where there is no clear Advance Care Plan, emergency treatment will generally be initiated. This may include intensive care admission. Such an approach enables the reversibility of the condition to be established, provides opportunity to establish the patient's wishes and time to reach a consensus about an appropriate treatment plan.

When emergency treatment is instituted under circumstances where early review is anticipated (that is, where there is any doubt about the appropriateness of intensive treatment), it is important that the family are made aware that a reassessment will occur and that the treatment plan may change.

It is important to establish how a particular individual wants decisions to be made. Some patients expect to make decisions by themselves while others prefer to delegate this responsibility to others (to an individual family member or to the family group as a whole). Others may prefer to delegate to the doctor. There may also be degrees of delegation, some delegating the whole decision-making responsibility with others wanting particular wishes to be taken into account. Understanding decision-making expectations is important to avoid misunderstanding.

Sometimes treating doctors avoid giving a realistic prognostic outlook to patients or families, often in the belief that this maintains hope. It is important to recognise that overestimation of the prognosis by the patient or family can lead them to make ill informed, inappropriate treatment choices. Where patients and families are involved in decisions it is essential that the information on which they are basing decisions is as accurate as possible.

The informal use of untrained interpreters such as other family members should be avoided where possible, as they can easily confuse their role as translator and family participant and they can also misinterpret the clinical information (for more information about use of interpreters see section 5.6).

### Case example

A 24-year-old man has had a head-on collision in rural Australia and is taken to the local base hospital. The injuries sustained include severe head and cervical neck injuries. The initial scans show a complete C1/C2 dislocation and spinal cord compression together with diffuse, severe intracranial injury with early evidence of coning.

The family demand he is sent to the city hospital that specialises in head and spinal injuries. The medical staff explain that this will not change the outcome. The family becomes upset.

The family is shown the scans and the hopeless prognosis is carefully explained. They are informed that expert specialists in the city hospital have been consulted and that they have viewed the investigations. The family is reassured that treatment options available in the city will not result in a different outcome.

The disadvantage of the young man being removed from the family (to die) is highlighted.

The family is given the opportunity to talk with the specialist in the city hospital.

The young man dies with his extended family present. After the event the family thank the doctors for giving them the opportunity to all be present and for not sending him away to die.

### Issues:

- Rural hospitals have fewer services than the city hospitals. This is known in the community. With sudden devastating injuries, it is understandable for relatives to expect that 'everything' is being done and there is a common belief that this will include transfer to specialised city hospitals.
- Such expectations need to be specifically recognised and addressed.

### Resolution:

- Trust needs to be established.
- When relatives are in 'rescue mode' and expecting 'everything', medical staff need to support and guide them through this stage.
- City (tertiary) treatment and opinions can be brought to rural areas through consultation but the patient does not have to be transferred for this to happen. This is especially pertinent where transfer has no benefit and could harm the patient or relatives.

### ANZICS recommendation:

All discussions of end-of-life care should take place in a context of mutual respect for all participants and this context should be actively sought and supported.

### 5.3.3 Communication strategies that help build consensus

Discussions with patients and/or their families about treatment limitation should ideally occur in stages over a period of time.

At these discussions, the presence of nursing staff or key members of other medical teams such as a social worker or chaplain is recommended. A social worker or chaplain may be able to devote more time to the family than is possible for nursing staff, and may be felt by family members to be more neutral than the medical team.

Where possible, it can be useful to have the same doctor communicate with the patient or family on behalf of other medical teams throughout the discussion process, as minor differences in explanation of the patient's condition or progress can seem to patients and families like major disagreements or a sign of discord in the team. Ideally, this health professional should be senior and experienced in conducting such discussions and should have earned the trust of the patient or family before treatment limitation is discussed. When this is impractical, close liaison between those doctors speaking to the patient or family is essential. Establishing what the family have heard from previous meetings is also essential before providing more information (what families 'hear' can differ from what doctors think they have said).

The phrases 'do everything' or 'do nothing' should be avoided. These terms are never strictly enacted and such terminology is a barrier to informed discussion. Appropriate discussion should include consideration of the benefits and burdens of various courses of action.

The goal of providing comfort to the dying patient should be emphasised. Additional reassurance might include statements that the team will remain involved and that the family will be supported.

For additional suggestions about strategies when English is not the first language or when treating people who have cultural concerns that are poorly understood, see section 5.6. In these circumstances, even more care must be taken with conversations.

#### **5.4 Planning and conducting an effective family meeting**

Building a relationship of mutual trust and respect with the family is a key part of successfully managing the care of a patient at the end of life. Meetings should occur early in the course of an illness, particularly where death is a possible outcome. Recognising and communicating the possibility of death allows families to understand the severity of the illness and recognise that prolonging life should not be the only goal. It is likely that there will be several meetings over the course of an illness and where possible a consistent medical person should be involved.

Practical aspects of the meeting include:

- The intensivist should visit the bedspace and update themselves on the condition of the patient and any recent input from other medical teams immediately prior to the meeting. This may include a review of the patient notes.
- The intensivist should ascertain the preferred name of the patient (although this should be checked at the start of the meeting).
- Meetings should occur in a private room that is designed for this purpose.
- Adequate time should be allocated for the meeting. During the meeting, the family should receive undivided attention from the doctor, free from interruptions from pagers, phones, people and intercoms.
- The medical team should always involve the intensivist and bedside nurse. Junior medical intensive care staff are encouraged to attend, both for continuity and as a training

opportunity. Other team members who may attend include representatives of other medical teams, social workers, clergy, cultural leaders and interpreters. Care should be taken that hospital staff do not significantly outnumber single people or small family groups.

- An ICU team member should always be involved in meetings that are organised by other medical teams and that involve the family of a patient on intensive care.
- Ensure that all members of the medical team have a consistent message prior to starting the meeting and that each member understands their role. The bedside nurse should be present as a support person for the family rather than the 'bearer of bad news'.
- Ensure that all key family members are present before starting the meeting. The family will decide which family members should be present.

The content of the meeting should include:

- introducing the family members and the medical team
- finding out the preferred name of the patient (and asking permission to use this name)
- finding out what the family understand so far
- delivering new information in simple everyday language and avoiding medical jargon
- emphasising the continued care of the patient when treatments are being limited or not offered
- showing empathy, active listening and allowing for silences as important ways of communicating compassion
- encouraging questions and answering them truthfully and fully, acknowledging that families may think of questions beyond the meeting and can still access the medical staff.

Effective communication skills can be continually improved through practice and learning.

**ANZICS recommendation:**

All staff involved with the dying ICU patient should undertake education in how to communicate effectively with critically ill patients and their families around the end of life.

#### **5.4.1 Inappropriate requests for continuing treatment**

The management of this sort of discussion is complex. It is more likely to occur when the family has reason to believe that the decision-making process is not respectful of the interests of the patient. This is especially likely where the worth of the patient is seen to be devalued, or when there is any suggestion that resource access is being restricted. This perception is minimised where the individuality, the interests and wishes of the patient are highlighted in respectful unhurried family conversations, away from the bedside and in a quiet and undisturbed environment.

Families who feel well supported and whose views are have been thoughtfully solicited and acknowledged are more likely to believe that the patient is being respected and well cared for.

#### **5.5 Recommendations for communicating end-of-life concepts**

Members of medical teams and doctors might not always be aware of how their words might be misunderstood by patients and families, especially during end-of-life discussions. Careful

consideration of language is essential to reduce psychological distress and to aid consensus building. The table below gives concrete suggestions of statements that can help to address some of the usual misunderstandings.

<b>Table 5.1: Recommended language for communicating end-of-life concepts</b>		
<b>Poor statement</b>	<b>Possible interpretation by family</b>	<b>Better statement</b>
<i>Do you want us to do everything?</i>	Do you care whether they live or die? Do you want us to try?	<i>We want to work out what is the right thing to do.</i>
<i>What do you want us to do?</i>	It is the family's responsibility to decide medical treatment – not the patient or doctor.	<i>What would he or she want?</i> OR <i>What do you think he would want us to do?</i>
<i>We need your permission or consent to stop.</i>	The family have total control of decision-making.	<i>I would like to discuss with you whether it is appropriate to keep on...</i>
<i>There is nothing more we can do. We are withdrawing treatment.</i>	Abandonment.	<i>We will do everything we can to ensure his or her last days are as comfortable and dignified as possible.</i>
<i>We are going to withdraw care.</i>	The medical staff do not care.	<i>We are recommending making comfort a priority and to stop doing unpleasant things that are not helping.</i> OR <i>We are recommending continuing good care while stopping treatments that are distressing and not helpful.</i>
<i>Futile treatment</i>	Your relative's life is futile/worthless.	<i>Overly burdensome or ineffective treatment.</i> OR <i>Treatment that is ineffective and distressing.</i> OR <i>Treatment that is worse than the disease itself.</i>

<b>Poor statement</b>	<b>Possible interpretation by family</b>	<b>Better statement</b>
<i>We can't be certain...</i>	Things are too uncertain for important decision-making.	<i>We are as certain as we can be.</i> OR <i>There are some things that we can't be sure about but other things that are very clear. (i.e. focus on the most certain facts rather than on the least certain).</i>
<i>The medical team have decided...</i>	The family and their views do not matter at all.	<i>We are becoming concerned that the burden of continuing this sort of treatment outweighs the benefit. I am afraid the treatment is not working.</i>
<i>We could do this or this or that... (the 'shopping list').</i>	The family have the power and responsibility to decide. Continued treatment is being offered and advocated by the doctor.	<i>There are lots of treatments that we could do but it is important for us to discuss what we should do.</i> OR <i>We could theoretically do a number of things but I should like to discuss what we should actually do.</i>
<i>Terminal care.</i> OR <i>Comfort care.</i>	Clichés that obscure meaning.	<i>Reset our focus to ensure his or her end is as comfortable and dignified as we can make it.</i> OR <i>Reconsider our goals to make comfort the priority.</i>
<i>There is a lot of misinformation on the internet.</i>	Family efforts to get information are being derided.	<i>Can you show me what you have found so we can discuss it?</i>
<i>This is not euthanasia.</i>	He is talking about euthanasia and using a controversial, highly emotional, weighted word.	<i>Permitting to die (with a specific explanation of what is proposed).</i>

## 5.6 Using translators and cultural leaders for end-of-life discussions

### 5.6.1 Language differences

#### Case example

Mrs Yeo is an 89-year-old Chinese national who has suffered a massive CVA while visiting Australia. Her immediate family speak no English.

A family meeting has occurred where a family friend translated. Despite the hopelessness of the prognosis the family remain adamant that treatment should be continued and seem confident that she will fully recover.

#### Issues:

- Unprofessional translation leaves the medical team unsure of exactly what the family have been told. A family friend is likely to have ‘sugar coated’ the message in the belief that this is kind or because this is culturally appropriate.

#### Resolutions:

- Use a professional translator and ensure that they appreciate the expectation of literal translation and the importance of not ‘softening’ the message.
- Also ensure that there is another person in the meeting who is an English speaker but also understands the language of the family and will be able to confirm appropriate translation.

Language and the manner in which concepts are conveyed are important in end-of-life discussions. Subtle changes in the way words are translated can alter the meaning of conversations.

In conversations on end-of-life issues, doctors need to be consistent with the culture of medicine, only offer treatments that will be best for the patient and understand the patient’s priorities. It is important to convey the following messages to the family:

- why medical decisions have been made
- the implications of those decisions
- medical decisions are made in the best interests of the patient.

The understanding from both sides is more difficult when English is not the first language and when the cultural context of ‘the other side’ is poorly understood. Even more care with the conversations must be taken in these circumstances.

When English is not the first language, or is poorly understood, it is important to use a translator to ensure that the message has been understood in both directions. Equally important is an understanding between the doctor conducting the end-of-life discussion and the translator who is translating, to ensure that what is conveyed in English has the same meaning when translated into a second language.

## **5.6.2 Managing a meeting with family and translators**

### **5.6.2.1 Choosing a translator**

In general, the informal use of untrained translators such as other family members should be avoided where possible as family can easily confuse their role as translator and family participant and they can also misinterpret the clinical information (for instance, to soften the impact). The use of family members as translators should ideally be restricted to discussion of 'housekeeping' matters. It is often useful to indicate to the family that a translator has been arranged to assist the intensivist, rather than to assist the family, in order to avoid the family responding that they understand well enough and do not need a translator.

Ideally, formally trained translators should be booked for meetings with patients and families. It is preferable for the same translator to be used when more than one meeting is required.

Other options for help with translating meetings include:

- consulate staff – they are diplomats and can add a useful perspective
- internal staff members from the health organisation (for example, doctors) who speak the language of the family.

### **5.6.2.2 Before the meeting**

Doctors should meet with translators before meetings to ensure that the translators understand the clinical issues and the upcoming task. Emphasise to the translators that they should translate as literally as possible and that they should not add their 'interpretation'. It is also important to establish that the translator sees no cultural barriers to full and frank translation.

It is preferable to try to explain these issues to a translator in a 'pre-meeting' rather than during the meeting, when the family is present.

### **5.6.2.3 During the meeting**

The translator should simply act as the conduit for the conversation and translate the words verbatim. The intensivist should maintain focus and eye contact with the patient or family member and use the same language as if speaking to them directly. For example, 'Tell me how you are feeling today' rather than 'Can you ask her how she is feeling today?'

If possible, intensivists should ask an English-speaking member of the meeting who understands the language into which the English is being translated (who is preferably a staff member, but may be a family member) if they believe that the translator is communicating the same information as the intensivist.

During the meeting with the family, if intensivists notice moments when the translator and the family commence what appears to be a separate or additional dialogue, then intensivists should ask to have this additional discussion translated back to them. Misunderstandings often occur during these additional discussions.

The added complexity of a translator adds time to such meetings and intensivists will need to be conscious of talking more slowly and allowing longer for these meetings to occur.

#### 5.6.2.4 After the meeting

Another meeting with translators after the session can be important to gather the translator's feedback and cultural insights about the dynamics for each particular family.

**ANZICS recommendation:**

Intensivists should use patient-focused and family-focused language and involve cultural advisers and translators where the cultural or language differences might impede communication and understanding.

#### 5.6.3 Cultural and religious differences

Cultural leaders are also important when the discussions are with a group who have cultural concerns that are not fully understood by the doctor. Prior to conducting the discussions, a meeting between doctor and a cultural leader must be conducted to ensure that the cultural leader will be able to discuss the required issues. Some examples of problems that can occur:

- Female cultural leaders may not be able to convey information that is traditionally considered men's business (or vice versa).
- Cultural leaders may not be able to convey the same message as the doctor because the cultural norm is to never say someone is dying because that would curse that person.

Where individuals profess a religious affiliation, it is very important not to assume that they accept everything that characterises that particular religion. Some individuals may take a fundamentalist position while others may only adhere to a few superficial concepts. In every case where religion impacts on decision-making, the beliefs of the individual patient should be explored.

**Case example**

A 72-year-old Aboriginal female elder who is responsible for bringing up five grandchildren presents with a urinary tract infection. She has septic shock that is not responding to fluid resuscitation.

She refuses to have a central line inserted so she can have inotropes, as she does not want to come to intensive care.

When the medical staff talk with her she states she wants to go home to country and die. Doctors cannot get any other information.

The Aboriginal liaison officer extends the conversation and explores why she does not want to go to ICU. They discover that she is convinced that she will die in ICU. Her sister died in ICU and she is terrified of her sister's spirit in the unit. She says if she is going to die she wants to go home to country. She also believes that the treatment will not work, that it will place her in a spiritually unsafe place and that she will then be unable to die in country.

The doctors explain (using the liaison officer) that treatment has a high chance of making her better. They explain that they have already started some treatment to support her blood pressure and this had partially stabilised her. They explain that the safest place to have this treatment is in ICU.

The doctors find out in which ICU bed the sister had died and tell the elder that they will put her in a different part of the unit and that if the family wish, they could call the Ngungkari (witch doctor) to help 'clean' the ICU of the spirits she was worried about. The staff also reassure her that if the treatment does not work then they will try to get her back to country.

The Aboriginal elder agrees to this plan.

The Aboriginal elder recovers after two days and subsequently persuades other Aboriginal people to have treatment in ICU.

**Issues:**

- Australian hospitals are not always culturally safe.
- The fact that specialist treatment may help is not always understood.

**Resolution:**

- Decisions to not have treatment that may help are often made without full knowledge.
- Establishing understanding with cultural leaders is important.
- All spiritual beliefs need to be respected.
- Ngungkari (Aboriginal Traditional doctors) often help people to seek and accept Western medical care.
- Cultural needs such as getting back to country should be respected. However, when that need endangers the person, full understanding of the risk between patient and doctor needs to be established. These wishes to go back to country may be a symptom of desperation and a misplaced feeling of hopelessness in the patient.

## 5.7 Documenting the agreed management plan for end-of-life care

Once consensus has been achieved among the medical team and the patient or patient's family, the agreed care plan should be documented in the case notes. Thorough documentation of decision-making processes provides transparency and accountability and ensures that health professionals fulfil their professional and legal obligations. Information should be conveyed to all stakeholders.

Intensivists should be familiar with any documents related to end-of-life planning and the status of the substitute decision-makers according to the state guardianship laws.<sup>106</sup> Whether the documentation occurs on standardised hospital forms or in the written notes, it should include the following information:

- time and date of meeting
- persons involved in the discussion
- medical facts leading to the decision, including prognosis
- statement of the patient's wishes and how these were determined, including the presence of an Advance Care Directive/Plan
- options discussed, agreed goals of treatment and what consensus was reached
- why it has been agreed that this is the appropriate course of action
- what treatments are to be withheld or withdrawn
- what treatments are to continue, including medications and symptom relief
- whether organ or tissue donation has been considered as a possibility
- with whom the plan has been agreed and their designation.

If the patient does not have capacity and it has not been possible to find one of the documents (standardised hospital forms or written notes) or individuals in time, the documentation and treatment should occur with the appropriate medical consensus and in line with good medical practice.<sup>107</sup>

### **ANZICS recommendation:**

End-of-life decisions should be formally and clearly documented and communicated to all stakeholders. Compliance with documentation should be regularly audited.

<sup>106</sup> Australian Guardianship Law, *Discovering Australian Guardianship law*, website, <http://www.austguardianshiplaw.org/>.

<sup>107</sup> Medical Board of Australia, *Good medical practice: a code of conduct for doctors in Australia*, March 2014, <http://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx>.

Medical Council of New Zealand, *Good medical practice*, April 2013, <https://www.mcnz.org.nz/news-and-publications/good-medical-practice/>.

## Chapter 6 – Managing conflict

### 6.1 Overview

This chapter presents information about:

- 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.

Disagreements can arise regarding treatment limitation decisions, or about other aspects of end-of-life care. Disagreement is defined as difference of opinion. Conflict is serious disagreement or argument.

Most disagreements between the medical teams, the patient or the family can be prevented by early, sensitive and proactive communication that clarifies goals of treatment, possible outcomes and aligns the treatment plan with the patient's values and wishes (see Chapter 5). Listening and empathising with the concerns of the other party is an important way of trying to understand and manage any disagreements.<sup>108</sup> Conflict within ICU can be damaging to the staff, patients and families involved and is best prevented or managed early to avoid the longer-term negative effects.

### 6.2 Strategies for resolving conflict

#### 6.2.1 Achieving medical consensus

##### Case example

A 36-year-old man re-presents to ICU with overwhelming neutropenic fungal sepsis during his third relapse with poor prognosis myeloid leukaemia.

The ICU team consider that there is no reasonable chance of survival while the haematology team are adamant that aggressive treatment is appropriate since they feel that there is 'a reasonable chance'. It is documented that the patient wants any treatment that is offered.

##### Issues:

- Decision-making in uncertainty.
- Achieving consensus in the setting of conflict.

##### Resolution:

- Conflict resolution should focus on the importance of listening and adjust opinions.
- Seek second medical opinions or agree to a trial of treatment.
- Show collegiate respect and, if required, engage a senior respected colleague to assist.

<sup>108</sup> AC Long & JR Curtis, 'The epidemic of physician-family conflict in the ICU and what we should do about it', *Critical Care Medicine*, vol. 42, 2014 pp. 461–462, <http://www.ncbi.nlm.nih.gov/pubmed/24434450>.

Achieving medical consensus (including consensus with nursing staff and other clinical staff) is important because it enables a clear, agreed recommendation to be presented to the patient or family. A medical consensus that withdrawal is appropriate is also protective of individual decision-makers in the event that there is a complaint.

It is important that doctors avoid giving inconsistent, or contradictory, information to the patient's family, especially where professional disrespect is implied.

Regular meetings between those treating doctors who meet with the family are highly desirable as this facilitates consistent messages being provided to the family and consistent documentation in notes.

It is strongly advised that intensivists are present when other specialists or members of other medical teams speak to the family of patients undergoing treatment in ICU. This reduces the risk of inconsistent messages being delivered to the family.

It is important that doctors understand and respect genuine clinical disagreement that can occur among clinicians while, at the same time, recognising the need to reach (and to abide by) a reasonable clinical consensus.

Important pre-requisites for successful resolution are willingness to negotiate, a desire to remain objective and, at all times, to retain a clear focus on the best interests of the patient.

Conflict can occur and is a source of considerable burden to staff and the families of critically ill patients. It has been associated with symptoms of post-traumatic stress and 'burn out'.<sup>109</sup> Disagreement about the goals of patient treatment is the most common source of conflict among ICU staff.<sup>110</sup> Disagreement about prognosis is also common.

ICU nurses and doctors may feel disempowered where they are forced to carry out treatments they believe are not in the best interests of the patient at the behest of families or other medical teams. This can lead to a rather fundamental moral conflict with short- and long-term adverse consequences for morale and future interaction.

Active programs for staff support should be a part of the routine functioning of ICUs with professional counselling or supervision available for those with high levels of exposure to complicated or fraught end-of-life decision-making situations.

There is a belief that intensive care doctors are innately pessimistic<sup>111</sup> and other medical teams are overly optimistic.<sup>112</sup> Intensive care specialists and other medical teams need to be mindful of the

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<sup>109</sup> Medscape, 'Intensivist lifestyles – linking to burnout: A Medscape survey', 2013, [slideshow].

N Embriaco, E Azoulay, K Barrau et al., 'High level of burnout in intensivists: prevalence and associated factors', *American Journal of Respiratory Critical Care Medicine*, vol. 175, 2007, pp. 686–692, <http://www.atsjournals.org/doi/full/10.1164/rccm.200608-1184OC-.VFBSx9bypZo>.

<sup>110</sup> E Azoulay, JF Timsit, CL Sprung et al., 'Prevalence and factors of intensive care unit conflicts: the conflicus study', *American Journal of Respiratory and Critical Care Medicine*, vol. 180, 2009, pp. 853–60, <http://www.atsjournals.org/doi/full/10.1164/rccm.200810-1614OC-.VFBJ9bypZo>.

<sup>111</sup> MJ Wildman, C Sanderson, J Groves et al., 'Implications of prognostic pessimism in patients with chronic obstructive pulmonary disease (COPD) or asthma admitted to intensive care in the UK within the COPD and asthma outcome study (CAOS): multicentre observational cohort study', *BMJ*, vol. 335, 2007, p. 1132, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2099544/>.

<sup>112</sup> P Glare, K Virik, M Jones et al., 'A systematic review of physicians' survival predictions in terminally ill cancer patients', *BMJ*, vol. 327, 2003, pp. 195–198, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC166124/>.

prognostic uncertainty of serious illness and of the primacy of the personal values of the patient with respect to burden, benefit and acceptable quality of life.

All doctors need to be constantly mindful of their potentially conflicted position (especially in the setting of iatrogenic complications).

Candid, honest and mutually respectful communication is the best strategy to resolve conflict between doctors and families. On rare occasions, second opinions or mediation may be required where convictions become intractably opposed.

To summarise, conflicts between medical staff about withholding or withdrawal of treatment can be a result of a number of factors including:

- disagreement about prognosis
- differing concepts about what represents treatment 'success'
- differing understanding about what the patient wants
- personal cultural and religious beliefs that influence willingness to accept treatment limitation
- personal reluctance to accept death as an outcome
- guilt (common in the case of iatrogenic complications)
- concerns about coronial, administrative or legal reporting requirements
- emotional overlay (often in the setting of previous, unsatisfactory, unresolved interactions among clinicians).

#### **6.2.1.1 Practical suggestions to aid medical consensus**

Misunderstanding may be avoided if the other medical teams visit the ICU frequently and are kept informed of progress (or lack thereof).

It is important to recognise that no individual doctor has the right to veto the view of other clinicians (this applies to intensivists as well as referring specialists). It is useful to consider how much weight it is reasonable to attach to each specialist's views in coming to a consensus. A clinician who has previously cared for the patient over a period of time can clearly provide useful input, as may specialists with special expertise in the prognosis of particular diseases. Where patients have spent significant time in ICU, the view of the intensivists should assume significant weight as they have special expertise in relation to the risks and benefits of intensive care treatment. At the same time, emotional involvement, guilt and personal needs can cloud objectivity.

Doctors frequently consider only the chance of survival when considering the appropriate treatment option. However, the burden of treatment, anticipated duration of treatment and likely outcome are also very important considerations for patients and families. Doctors should include these factors in their considerations.

As part of the process of agreeing what treatment is appropriate, it is vital that the patient's preferences should be elicited and respected. Patient wishes are important determinants of the patient's best interest and should be given great weight.

When there is a single dissenting doctor it may be helpful to request that they find a peer who agrees with their position and bring this colleague to a meeting with the other doctors with whom they are in dispute. Colleagues are generally unwilling to support inappropriate positions and the attempt to muster support often reveals, to the intransigent doctor, the weakness of their position. Where found, a supportive colleague is more likely to be able to suggest some scope for compromise than the original dissenting clinician.

Where there is doubt about the medical prognosis, advice should be sought from other senior clinicians who have experience in the condition. These opinions should be documented. A second opinion from a respected colleague, who is uninvolved with clinical management, can assist to resolve conflict – while ‘maintaining face’ for the clinicians involved.

An experienced medical specialist (who is not necessarily an expert in the clinical condition), who is respected by all parties and has good negotiation skills, may also prove useful as a mediator.

In the case of ongoing difficulty, the doctors involved should be made aware of the further measures that are likely to ensue should it prove impossible to reach a consensus that is acceptable to the medical team. Such escalation is likely to lead to involvement of the Divisional Head, Medical Administration and/or Human Resources.

#### **6.2.1.2 Managing conflict with other medical teams**

Conflict with other medical teams regarding end-of-life decisions, if not resolved, can recur. Often, where a procedure or operation has been undertaken, the proceduralist or surgeon may find withdrawal of treatment difficult, particularly if they have invested much time and effort into the therapy.

A lot of emphasis is placed on ICU staff having empathy for patients and relatives, with little emphasis on empathy for other health practitioners who have a different, and often longer, relationship to the person dying than the ICU team. It is worth trying to understand the potential influence of the other clinician’s culture, religion and personality on their decision-making. Without empathy for non-ICU staff, problems will tend to recur and escalate.

#### **6.2.1.3 Codes of Conduct and medical consensus**

Clinicians should be cognisant of the need to adhere to good medical practice as defined in their relevant Code of Medical Practice: *Good Medical Practice: A Code of Conduct for Doctors in Australia*<sup>113</sup> (Medical Board of Australia) and *Good Medical Practice*<sup>114</sup> (Medical Council of New Zealand).

Good medical practice requires doctors to communicate effectively with other team members and to understand the nature and consequences of bullying and harassment. Both of these requirements are likely to be compromised where a doctor upholds an intransigent position, particularly where there is refusal to engage in negotiation with medical colleagues or where threats are made.

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<sup>113</sup> Medical Board of Australia, *Good medical practice: a code of conduct for doctors in Australia*, March 2014, <http://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx>.

<sup>114</sup> Medical Council of New Zealand, *Good medical practice*, April 2013, <https://www.mcnz.org.nz/news-and-publications/good-medical-practice/>.

Some doctors may hold a conscientious (or religious) objection related to the contemplated end-of-life management. In such a circumstance, the doctor should declare the basis of their objection and should remove themselves from that aspect of care.

There should be no tolerance of bad behaviour including intimidation, harassment or bullying.

Practical responses to this include:

- reporting the behaviour to the ICU Director
- arranging a meeting between the ICU Director and the non-ICU doctor and, if necessary, the non-ICU doctor's Director and/or the hospital's chief medical officer.

### 6.2.2 Disclosure to patients and families

#### Case example

An 87-year-old woman undergoes an aortic valve replacement. She then suffers multiple complications during her post-operative course and is unable to be weaned from ventilation or inotrope support during the subsequent two weeks. She appears to be deteriorating.

The ICU team share consensus that there is no reasonable chance of survival.

The cardiac surgeon states that he forbids any consideration or discussion of withdrawal for 'his' patient and states that he would consider any discontinuation as 'murder' and would take action accordingly.

#### Issues:

- Refusing to acknowledge alternative medical opinions.
- Depriving the patient (and/or family) the opportunity to participate in informed decision-making by withholding alternative medical opinion.
- Threatening other staff involved in the care of the patient.

#### Resolution:

- Ensure that there is consensus within the intensivist team.
- Point out to the surgeon that the patient and/or the family have a legal right to know all medical opinion in order to make informed decisions.
- Point out to the surgeon the advantages of a single consensus medical decision, but if this cannot be achieved, that patient/family need to be presented with both opinions.
- Express empathy with the surgeon in his disappointment with the outcome of his efforts, and the patient's predicament.
- Ask the surgeon to get a second opinion from among his colleagues.
- Point out to the surgeon that bullying, harassing and threatening other specialist medical staff is absolutely unacceptable.

Honest information in non-technical language should be provided to patients and their families to enable them to participate meaningfully in decisions about end-of-life care. All clinically appropriate options (choices for which there is a responsible body of medical opinion) should be discussed.

For suggestions about language to use when speaking with patients and their families, see Chapter 5.

Requests by family that the patient should not be informed must be managed carefully. In this situation, it is appropriate to inform the family that the patient has a right to choose whether they want to be fully informed or whether they want the health professionals to only discuss their condition with the family. It is also worth reassuring the family that most patients do want to be informed and that intensivists will be careful and compassionate in their explanation to the patient. It is also appropriate to inform the family that, in fact, the doctor should be seeking the permission of the patient before divulging personal information about the patient to the family.

The most practical way to respect the rights of the patient and keeping the family on side is to advise the family that intensivists will ask the patient, with the family present, if they wish the doctors to inform them regarding their condition or whether to only discuss their condition with their family and not them. Most patients do not want to be excluded and in this situation the patient's preference for inclusion must be respected.

A few patients, however, want to be protected from information and expect the family to take on the decision-making role. This is acceptable if intensivists have no doubt that the patient is making this decision freely and without coercion and as long as intensivists point out to the patient that, by delegating the receipt of information, they are also delegating decision-making to a family member as a substitute decision-maker. At such a time it is essential that the patient identifies their chosen substitute decision-maker. If these issues are not clarified, there is a significant risk that inappropriate treatment may be given where patients give consent in ignorance of their clinical situation.

The temptation to provide an overoptimistic prognosis to maintain hope is not acceptable, especially where this results in misinformed decisions. Most patients and families expect, and appreciate, an honest assessment when they are involved in the decision-making process.

The wish to avoid burdensome treatment or to avoid dependency is often as important, or more important, to patients than is the chance of survival, so it is essential that likely outcome is included in the discussion.

Patients and families are often shocked and affronted when conversations about the goals of care and treatment cessation occur late in the course of treatment without preparation. This is particularly the case when patients have received an overoptimistic assessment of prognosis throughout the illness. Patients and their families should be engaged in open communication about possible (and probable) outcomes early in treatment, especially where the patient is seriously or critically ill. Early, honest and regular communication can also help create the trust needed for shared decision-making.

The word 'die' should be used whenever death is a possibility. Here are some phrases where the words 'death', 'die' or 'dying' are used:

*He is very likely to die from this. We are doing [insert treatment]. We should have another talk in the morning and tell you whether or not his situation has changed.*

*This is something people can die from. We are giving him the best treatment we can and we will just have to see how he responds as time goes on.*

*He is in ICU because this is life-threatening, in other words, he could die from this. We usually manage to get people like this through it, if nothing else goes wrong. No guarantees though. We will talk to you about his progress in the morning.*

### **6.2.3 Expressed wishes and substitute decision-making**

Doctors and families have to make decisions based on the best available evidence of the patient's wishes and this is often less clear than would be desirable.

The wishes of a patient who lacks capacity about future treatment can be deduced in various ways. These range from extrapolation from how they have led their life, to general statements that they have made during their life, up to formal legal documentation with the appointment of a well-informed substitute.

There should always be an effort made to identify people responsible for participation in end-of-life decision-making. In Australia, there is a hierarchy of 'closeness' of relationship that determines the authority of individuals within the family to make treatment decisions. Some Australian states publish a formal hierarchy (for an example, see section 2.2.2.1). There is no such legal hierarchy in New Zealand.

The views of a person who has been specifically (legally) appointed by the patient to represent them in medical decision-making should carry significant weight. However, the appointed substitute should engage in a shared decision-making process (both with other medical teams and with the rest of the family).

Advance care planning can include both written Advance Care Directives and formal appointment of substitutes to make decisions (when the patient is unable to do so).

However, advance care planning may be inadequate to provide the degree of certainty that doctors and families seek to support their end-of-life decision-making. The views expressed in advance may not be directly relevant to the current situation and many Advance Care Directives contain the phrase 'no reasonable chance' which leaves the treating clinicians and family to try to interpret what the patient meant by reasonable.

It may be helpful to consider the validity of a patient's wishes in varying levels of (decreasing) reliability:

Level 1. A documented Advanced Care Plan relevant to the current situation that has been discussed with a nominated surrogate in a structured session.

Level 2. An Advance Care Plan that is relevant to the current situation.

Level 3. Informal discussions about the patient's wishes held between family, friends and the patient.

Level 4. Family and friend's belief that their knowledge of the patient enables them to determine what the patient would want.

Level 5. The physician's assessment based on limited knowledge of the patient concerned but knowledge of what others have wanted under similar circumstances.

## **6.3 Serious disagreements involving patients and families**

### **6.3.1 When a patient's family disagrees with a patient's decision**

The wishes of the adult patient who retains decision-making capacity are paramount (and remain paramount when these wishes are expressed in advance). If the patient's expressed wishes regarding active treatment or refusal of treatment are known, then these wishes should prevail over the wishes of the family.

It is important to try to explore why the family believes that overruling the wishes of the patient is necessary or why the family believes the patient's wishes are invalid.

### **6.3.2 Conflict within the family**

There are many potential sources of conflict within families. This is true of everyday life and is especially true when long-term relationships are tested by the emotion, fatigue and challenge to self-interest that having a critically ill family member entails. Vested (including dependence and financial) interests will vary within and among families but may be crucial to family responses. The intensive care environment may spawn positive emotional responses, but it is more likely that the stress will unmask pre-existing tensions and disagreements.

Occasionally, previously unknown relationships are unveiled and, for instance, spouses may discover the existence of new partners and must accommodate new realities. Critical illness may also unveil a patient's habits, practices or orientations that were formerly unknown to the family. This can also be a source of enormous anguish.

Religious convictions can become a source of contention and conflict, particularly when there has been a movement towards or away from more extreme or polarised convictions and practices.

There is no single solution to these issues. Many resources and initiatives may be required and this may necessitate controlling or rostering of 'family' interaction with the ICU. An awareness of the potential for family conflict is essential and the involvement of social workers, pastoral care workers, counsellors or other family supporters, and, even security officers, may all be required and helpful.

Engagement of cultural or religious elders can be beneficial.

At all times intensive care personnel should not lose sight of their primary responsibility to the patient while accepting that a duty of care may extend to the interests of the patient's family.

### **6.3.3 Conflict between families and the medical staff**

No matter how good the training of the communicator and the conduct of the family discussion, some families will always have a different perspective on the role of intensive care and end-of-life management. Some grieving families are simply unable to assimilate information no matter how well structured the communication and how much time is provided. Sometimes conflict can be predicted. It is especially likely where there is a cultural or interpersonal disconnect between the family and the medical team.

Early indicators of conflict regarding end-of-life care are:

1. Circular conversations. Characterised by end-of-life conversations in which the family avoids discussion of withdrawal and repeatedly revisit previous discussions. This is particularly common where conflicting information has been given or there have been significant

iatrogenic events contributing to the situation. The most useful solution to this is to have a break and to foreshadow the topic of discussion when the meeting restarts. This ensures that the relevant topic is the focus of the reconvened discussion.

2. Requests for second opinions. These requests should be encouraged. The family can be asked whether they wish the unit to arrange a suitable person or if they wish to find a suitable person themselves. It should be pointed out at this time that practitioners not authorised to practice in the hospital may require some formal authorisation and supervision. It should be recognised that families may seek second opinions from people without specific medical expertise, or whose opinions relate to ethnic and religious beliefs.
3. Requests to read the case notes. Such requests should be complied with, with the proviso that a member of staff assists the family to interpret entries and answer questions.
4. Family avoidance of the ICU team (sometimes visiting only out-of-hours).
5. Criticism of or rejection of individual team members (especially nurses) and accusations of not caring or incompetence. Requests may be made to transfer the patient to a different ICU.
6. Demands that specific treatments be administered or discontinued, particularly the withholding of opiates in the belief that they are being deliberately used to shorten life. Requests and demands may become more outrageous as the process continues.

Serious conflict of this type is more likely in the case of socially or culturally-isolated ethnic groups who perceive they are treated neither respectfully nor fairly by society.

When these signs occur there should be an immediate response as these events generally foreshadow increasing problems.

There are numerous different reasons why a family might make unrealistic demands for treatment. These need to be explored.

Families may expect treatment because they are unaware of the wishes of their relative, as patients may not clearly inform their families of their wishes and directives. As a result, doctors may be operating on information of which the family are unaware. Explanation that the treatment plan is based on the wishes of the patient can help to resolve the conflict.

Families who demand continued treatment may have unrealistic expectations about what can be achieved or have an excessively positive estimate of prognosis. This requires frank explanation.

Focus should always be kept on the best interests of the patient. Health professionals should ask those demanding treatment to explain why they believe the patient would want this course of action. This can reveal the weakness of the case or can helpfully elucidate the beliefs of this patient and their family.

More often, a demand for 'everything to be done' reflects unreadiness of the family to accept the inevitability of death. This situation is best avoided by early engagement in treatment planning prior to the onset of the dying process. Listening to the family's concerns often assists with acceptance. In most cases the family will come to accept within a day or so of receiving a sympathetic and clear explanation.

Family obstruction may sometimes be based on reluctance to be implicated in the decision (although the appropriateness of the decision to palliate may be understood). In this situation, the impasse is resolved by the medical team recognising the situation and then taking responsibility for the decision (thus absolving the family from responsibility for the decision).

In the face of a family request to continue treatment, it is advisable that treatment is continued until resolution is achieved; however this may be difficult.

#### **6.3.4 Potentially inappropriate requests for cessation of treatment by the patient or family**

Patients and family members may be provoked to request cessation of treatment because they perceive that the pain, suffering or distress is intolerable. In this situation, it is essential that efforts are made to adjust treatment to address the symptoms of concern.

Depression can also lead to a request to cease treatment. This should be routinely considered and where there is doubt about its role, the opinion of a senior psychiatrist should be obtained.

Requests for cessation of treatment may also be based on misinformed, excessively pessimistic, estimates of prognosis. This should be explored and where present, the explanation of the reality of the outlook will generally resolve the situation.

On occasion, a request for discontinuation of life support can result from a misinterpretation of the patient's wishes. This may occur, for instance, when a patient has expressed a wish not to be on long-term life support and this is interpreted as a wish not to have short-term resuscitation associated with a near 100% chance of full recovery. These cases require exploration of exactly what wishes the patient expressed together with an explanation of the short duration of the proposed intervention.

In many cases, it may be appropriate to negotiate an agreed plan of continuing treatment while further discussion is arranged, while acknowledging that sustained wishes for treatment refusal in the patient who has capacity are ultimately paramount.

### **6.4 Options for resolving disagreement**

#### **ANZICS recommendation:**

Preventing the development of conflict should be an integral part of any communication with patients, their families or other involved staff.

The following approaches are potential strategies for resolving disagreements associated with end-of-life care. Not all options will be available in all clinical contexts. However, they may provide guidance. Simple approaches should be taken first.

#### **6.4.1 Taking time and ongoing discussion**

Unless decisions need to be made urgently, giving families time to come to terms with the impending death of the patient is often sufficient to resolve disputes. Families need to come to an understanding at their own pace (often with discussion at home) rather than being forced by the medical team.

Wherever treatment is prolonged against medical advice, it is important to ensure that this does not result in undue suffering for the patient.

#### **6.4.2 Second opinion**

Discussions about discontinuation should be based on a consensus medical opinion involving a number of doctors and staff. This point should be explained to families. However, the concept of an 'external' second opinion is valid and may assist with resolution.

The family have a right to request a second medical opinion and may raise this with any member of the medical team.

When the family continue to question the diagnosis or prognosis it may also be appropriate for the medical team to offer a second opinion. This opinion should be from a health professional with relevant expertise in the patient's condition who is demonstrably independent from the medical team.

External opinions (organised by the family) may be very useful when they provide support for the medical opinion as these people have the trust of the family. In this context, a trusted GP with the same ethnic background is likely to understand the medical situation and is in a position to communicate this in a culturally appropriate way. Others, such as alternative healers, may not advance understanding.

It is very important that the medical team speak to those who are providing a second opinion, brief them and provide access to all results before they see the patient or family so that they have a full understanding of the clinical situation. It may be appropriate to refer to a clinical ethicist or a clinical ethics committee (not a research ethics committee). This can be reassuring to both staff and family and can avoid unnecessary legal action.

#### **6.4.3 Facilitation**

Involvement of a third party may assist to clarify and address the concerns of the patient and/or family members. A facilitator may also be able to find areas of agreement where an impasse has occurred between the family and the medical team.

The facilitator may be a senior member of the hospital administration, a senior health professional or another person agreed upon by those involved. The person should have sufficient seniority, be respected by all parties, have excellent negotiation and facilitation skills and should be demonstrably independent of the medical team.

#### **6.4.4 Patient transfer**

When the above steps fail to resolve a dispute, the practicality of transferring the care of the patient to another institution or another suitable treating clinician within the same institution should be investigated. However, this is rarely practical.

#### **6.4.5 Tribunal**

A tribunal (specific to each state, for example, the Guardianship Tribunal in New South Wales) may provide assistance in relation to end-of-life care for patients lacking decision-making capacity.

Advice may include whether it is appropriate for the tribunal to deal with an application for consent to a proposed treatment on behalf of such a patient.

Palliative care is a medical treatment, so consent may be sought for it to be provided to replace more active treatment.

The application must set out the proposed treatment and any alternative treatments, and the nature and degree of any significant risks associated with the proposed treatment and the treatment alternatives.

#### **6.4.6 Legal intervention**

The Supreme Court (or the Family Court of Australia in respect of children and young people under 18 years old) has jurisdiction to hear matters relating to treatment limitation decisions. For more information about the legal system, see Chapter 2.

Senior treating clinicians or their delegates may consider initiating a court action when they have concerns that the proposed treatment or treatment limitation conflicts with their duties as a medical practitioners (most commonly when continuation of the treatment is judged to be causing unacceptable suffering) and when all of the above steps have failed to achieve a resolution.

Before initiating a court action, the senior treating clinician should usually have:

- obtained a second specialist medical opinion in writing
- sought advice from the Guardianship Tribunal where the patient does not have decision-making capacity
- informed the hospital executive of the proposed referral
- received senior institutional advice (including advice from the hospital lawyer)
- discussed the planned course of action (that is, a referral to the Court) with the family.

Where the patient lacks decision-making capacity, family members or 'persons responsible' may decide to independently initiate a court action where they dispute end-of-life decisions.

Family members or the Person Responsible should be specifically informed that they have this option, especially when disputes arise and appear insurmountable.

The courts have rarely been involved in end-of-life issues in Australasia. However, the judicial decisions that have occurred have been thoughtful and sensible. If a court referral is deemed necessary by the institution, then the family should be offered financial assistance for costs incurred.

Where continuing and repeated conflict concerning end-of-life care occur within a particular organisation, this should be a trigger for an institutional review of policies and practices.

### **6.5 Strategies for dealing with more serious escalation**

#### **6.5.1 Personal threats**

In rare circumstances, the conflict may escalate to a point where personal threats occur. These should not be tolerated and it is important to assume that all discussions subsequently occur in the presence of witnesses. In some cases, it may be necessary to strongly support or replace members of the medical team if they feel threatened.

### 6.5.2 Involvement of hospital administration and outside organisations and individuals

During serious conflict, families may involve media, politicians, and statutory bodies. When the media become involved in end-of-life conflict, physician involvement should be very circumspect. News stories depend on, or at least emphasise, the sensational aspects of the story and rarely invest the time to unravel all of the various nuances. News stories certainly do not aim to resolve conflict. Individual doctors in Australia have been targeted by the media based on a poor understanding of the situation and a desire for headlines. For example, in the *Messiha* case in New South Wales,<sup>115</sup> a journalist passed off as a family member and was present in the room when the ventilator was disconnected.

It is best to avoid requests from the media to respond to patient complaints. Requests through statutory bodies should be answered promptly in consultation with colleagues. It is important for doctors to request copies of responses from third parties such as hospital administration. Requests from lawyers for personal records of the case should usually be met by explaining that the doctor has no personal records that are not in the patient's file.

If a complaint is made to the hospital involving a member of the staff, particularly with respect to conduct of end-of-life care, a medical defence organisation should be contacted. It is important to ask to see all correspondence between the hospital and the body managing the complaint so that the practitioner's viewpoint is presented accurately.

**ANZICS recommendation:**

Strategies for resolving conflict should be included in ICU-specific local guidelines on end-of-life care.

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<sup>115</sup> *Isaac Messiha (by his tutor Magdy Messiha) v South East Health* [2004] NSWSC 1061 (11 November 2004), <http://www.austlii.edu.au/au/cases/nsw/NSWSC/2004/1061.html>.

## Chapter 7 – Care of the dying patient, their family and the medical team

### 7.1 Overview

This chapter presents information about:

- caring for the patient
- caring for the family
- supporting the medical team.

Intensivists should aim to support all people involved in the case, including the patient, the family and significant others as well as the medical team and the ICU nursing staff.

The ICU nurse has a crucial role in caring for the patient, caring for the family and supporting the medical team.

### 7.2 Care of the patient

#### 7.2.1 Providing care while the patient is dying

Symptom relief is one of the primary objectives of medicine and should occur for all intensive care patients irrespective of whether they are in the dying process. Due to the imprecise nature of early prognostication, for the 11% of intensive care patients who die in hospital, symptom relief as part of the plan to treat, will transition into palliative care.<sup>116</sup> Once it has been agreed that all life-prolonging treatments should be withheld or withdrawn, a palliative care plan becomes the sole focus of patient care. Often it is agreed that only certain treatments are to be withheld, for example invasive ventilation, dialysis, inotropes or CPR. In such cases, the care plan should also document at what point palliative care should become the sole focus.

Intensive care will often be the location where life-prolonging treatment is being withheld or withdrawn and the ICU team should take a leadership role in the process. Some of these patients will die rapidly, while others will occasionally leave hospital.<sup>117</sup> Predicting time of death will often be uncertain. All interventions must be individualised to the needs of the patient and family. A variety of factors will influence what palliative care interventions are required. Issues to consider include:

- What are the patient's wishes regarding their care and needs near the end of life?
- What treatments are being withheld or withdrawn?
- Is the patient conscious?
- How dependent on intensive care support is the patient and how will they respond when supports are withdrawn?

<sup>116</sup> Australian and New Zealand Intensive Care Society, *Centre for Outcome and Resource Evaluation Annual Report 2010 – 2011*, 2013, <http://www.anzics.com.au/core/reports>.

<sup>117</sup> D Cook, G Rocker, J Marshall et al., 'Withdrawal of mechanical ventilation in anticipation of death in the intensive care unit', *New England Journal of Medicine*, vol. 349, 2003, pp. 1123–32, <http://www.nejm.org/doi/full/10.1056/NEJMoa030083>.

- Is the death imminent?
- What are the patient's analgesic requirements?
- What are the patient's anxiolytic requirements?
- What are the patient's requirements for treatment of dyspnoea or other symptoms?
- What are the family's requirements?

**ANZICS recommendation:**

The dying ICU patient's end-of-life plan should be individually tailored, holistic and documented.

### **7.2.2 Palliative intervention**

Palliative interventions can be broadly categorised into non-pharmacological and pharmacological measures. These should be administered through a multidisciplinary team approach including nursing staff, social workers, pastoral care and the family. The ability of family to be involved in the care at the end of life can be rewarding for both the family and the patient.

#### **7.2.2.1 Non-pharmacological interventions**

The emotional and spiritual support of the patient should occur throughout their intensive care stay. Practical aspects that need attention at the end of life include:

- optimising the bed space in terms of privacy and lighting
- accommodating visitors after discussion with immediate family
- considering the issue of a beloved pet visiting
- offering pastoral, spiritual or cultural cares
- discontinuing inappropriate interventions such as investigations and non-palliative treatments
- repositioning for comfort and airway noise
- palliative nursing care such as mouth care, eye care, skin care, bowel and bladder care
- considering staged de-escalation of respiratory supports
- deactivating implanted defibrillators and pacemakers
- maintaining physiological monitoring only to ensure patient comfort
- considering removal of tubes and monitoring devices
- continuation of monitoring from a remote location
- nasal or facemask air to assist in relief of dyspnoea in a conscious patient.

**Case example**

A 54-year-old female with a history of hypertension presents with a GCS of 4/15. She is intubated and ventilated in the emergency department. A CT scan of the head reveals a large left basal ganglia bleed that would not benefit from neurosurgical intervention. She is admitted to ICU for a period of observation and there is medical consensus that if she survives, she would have severe permanent disabilities. The family meeting reveals she has consistently said she would not want to be supported in the event of severe irreversible neurological injury. There is consensus that the ventilator should be withdrawn and that she should be treated with appropriate palliative care.

Her current condition off sedation is on minimal pressure support ventilation (30% oxygen) with a respiratory rate of 14, has a pulse of 74 with a BP of 160/80. Neurologically she has GCS of 4/15 and extends to pain on the right side, all cranial nerves are intact with an effective cough on suction. The medical team assess she is unlikely to die shortly after extubation and currently needs minimal analgesic/anxiolytic requirements.

**Issues:**

- Evaluating the patient's needs once extubated.
- Evaluating the family's needs.
- Preparing the family for likely events once extubated including likely time to death.
- Discussing the role of analgesics and sedatives at the end of life.
- Considering the suitability for donation after circulatory death and discussing with your organ donation agency.

**Resolution:**

- Enquire as to whether all family and friends who they wish to be present are present or informed and any religious or spiritual needs have been met.
- Explain the ventilator and other tubes will be removed to avoid any potential discomfort that these interventions can cause. The family will have free access to the bed space area and may wish to assist in some aspects of her ongoing care.
- Currently her analgesic and anxiolytic requirements are minimal and will likely remain so, medications will be used to relieve any discomfort or distress that occurs and not used to alter the time of her death. If the family are concerned that their mother is in distress at any point, the medical team will reassess her and act accordingly.
- Explain that once the ventilator is removed, their mother will breathe independently and although not distressing to her, it may sound noisy like snoring. Her heart will stop beating after her breathing has slowed and this will happen naturally when she is ready. It is likely that this will occur over a period of hours to days and intensivists will try to find a single room in the general ward area. If she is transferred to the ward, intensivists will let them know in good time and introduce them to the team looking after her. Her ongoing care will be unaffected by the move.

### 7.2.2.2 Use of non-invasive ventilation

Non-invasive ventilation (NIV) is a proven and established therapy for respiratory failure in a number of specific patient groups because of better patient comfort with reduced sedation requirements compared to invasive ventilation. Although it is not a proven and established therapy in palliative care at the end of life, it has been used because of its ability to reduce dyspnoea in acute respiratory failure. However, concerns exist that in some patients it is simply prolonging the dying process rather than managing the distress of dyspnoea.

For patients where it is agreed invasive ventilation is not appropriate but that NIV is to be used with the hope of survival, a clear consensus on the goals of NIV is vital.<sup>118</sup> In this group of patients, NIV has an active life-prolonging role but there should be appropriate symptom control and a clear understanding of when symptom control should become the only intervention.

The role of NIV as a palliative intervention has very limited evidence and studies have not yet been done looking at the quality of the death using NIV versus the usual treatment of analgesics and anxiolytics. Possible advantages include enabling the patient to communicate for longer and potentially keeping survival as an outcome. Disadvantages include the discomfort of NIV, medicalisation of the dying process and ambiguity in the aims of treatment particularly around when to discontinue NIV and when to introduce opiates and sedatives.<sup>119</sup>

The role of NIV in patients with a high risk of dying should therefore be patient specific and clearly defined. Intensivists should recognise that the role of NIV in symptom control at the end of life is at best limited and the focus should be on the other aspects of palliative care.

### 7.2.2.3 Discontinuing respiratory and cardiovascular supports

When withdrawing respiratory support or supplemental oxygen, the impact on the patient should be anticipated. Sudden extubation or removal of oxygen therapy may cause the patient to become acutely dyspnoeic, which can be distressing to family and the patient. Staged de-escalation of respiratory supports may assist in titrating treatment of the resultant discomfort. Eventual extubation of the patient has been associated with higher family satisfaction rates during end-of-life care.<sup>120</sup> Pre-emptive dosing of medications is appropriate to prevent any distress caused by the withdrawal of respiratory support or supplemental oxygen. Cessation of cardiovascular supports such as inotropes and mechanical devices will not cause discomfort and therefore staged de-escalation is unnecessary from that perspective.

### 7.2.2.4 Pharmacological interventions

Many patients will already be receiving sedative or analgesic medications as part of symptom control. Common symptoms in patients at the end of life that will require treatment include relief of pain, relief of agitation, relief of nausea, relief of dyspnoea and treatment of excessive secretions.

Pre-prepared medication sheets can be a useful and effective way of ensuring immediate access to appropriate medications. It should be made clear in the medical record which symptoms are being

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<sup>118</sup> JR Curtis, DJ Cook, T Sinuff et al., 'Noninvasive positive pressure ventilation in critical and palliative care settings: understanding the goals of therapy', *Critical Care Medicine*, vol. 35, 2007, pp. 932–9, <http://www.ncbi.nlm.nih.gov/pubmed/17255876>.

<sup>119</sup> E Azoulay, E Demoule, S Jaber et al. 'Palliative noninvasive ventilation in patients with acute respiratory failure', *Intensive Care Medicine*, vol. 37, 2011, pp. 1250–7, <http://www.ncbi.nlm.nih.gov/pubmed/21656292>.

<sup>120</sup> E Gerstel, R Engelberg, T Koepsell & JR Curtis, 'Duration of withdrawal of life support in the intensive care unit and association with family satisfaction', *American Journal of Respiratory and Critical Care Medicine*, vol. 178, 2008, pp. 798–804, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2566791/>.

treated. Which medications are appropriate and the dosages remain the responsibility of the treating clinician and it is vital they have familiarity with the drugs being used. Intravenous or subcutaneous medications, by bolus or infusion, are the most appropriate route. Neuromuscular blocking drugs have no role in symptom relief at the end of life and should always be used with adequate complementary sedation. Occasionally, neuromuscular blocking drugs are used as a medical treatment for the underlying medical condition, such as severe ARDS. When withdrawal of respiratory support is planned in these patients, the neuromuscular blocking agent should be stopped prior to extubation. In such cases, it would not be unusual to have residual muscle paralysis that would take a prolonged period to return. There is expert opinion stating that there is no requirement to wait and test for return of neuromuscular function in these patients although attention should be paid to ensuring adequate complementary sedation.<sup>121</sup>

#### Case example

A 68-year-old female is on intensive care with severe ARDS, bilateral bronchopleural fistulae and multi-organ failure. Her severe restrictive lung disease has been managed with continuous paralysis and heavy sedation to try to optimise her ventilation. Her condition has failed to improve over the past three weeks and the medical team have met with the family and explained that the chance of recovery is very poor and they recommend withdrawal of treatment. The family agree that this would be in keeping with the wishes of their mother when facing such a terrible prognosis.

#### Issues:

- In the context of multi-organ failure, residual pharmacological paralysis is likely to be present for hours or days after cessation.

#### Resolution:

- Adequate complementary sedation has ensured that she has not been aware of her situation during her ICU stay and the family should be made aware of this.
- The neuromuscular blockade is ceased and the patient dies shortly after extubation. The cause of death remains the underlying illness and complementary sedation ensures that there is no awareness during the dying process.

#### 7.2.2.5 Drug doses for palliative care and symptom relief

All drug dosages should be prescribed with an appropriate dose range and an as-required bolus dose. Patients who require an escalation of the dosage range should have clear documentation in the medical record to give a narrative as to which symptoms have been difficult to control and the action taken. The effective dose, including bolus dosing, will depend upon the patient's age, underlying organ dysfunction, previous opiate or benzodiazepine exposure, the current level of sedation, the underlying disease and the patient's wishes regarding sedation at the end of life. There is no maximum dose in relief of pain and suffering at the end of life and all dosing should be individualised and titrated to effect. Many patients will require minimal dosing and at all times the intent is to treat

<sup>121</sup> R Truog, JP Burns, C Mitchell et al., 'Pharmacological paralysis and withdrawal of mechanical ventilation at the end of life', *The New England Journal of Medicine*, vol. 342, 2000, pp. 508–11, <http://www.ncbi.nlm.nih.gov/pubmed/10675435>.

any pain and suffering and not to hasten death. Hastening of death through palliative medications is a major concern for clinicians. Although most palliative drugs have cardiorespiratory depressant effects in excessive doses, when used appropriately in palliative care scenarios, increasing doses of opiates have been associated with a longer time to death.<sup>122</sup>

Examples of commonly used medications (intravenous or subcutaneous, as appropriate) and adult dosages include:

- morphine for pain and dyspnoea
  - 1–10 mg/hour with a 5 mg iv bolus prn
- midazolam for agitation and restlessness
  - 1–10 mg/hour with 5 mg iv bolus prn
- haloperidol for delirium
  - 2–5 mg iv prn
- glycopyrolate for secretions
  - 200 µg iv prn.

Assessment and treatment of pain and suffering requires a multidisciplinary approach. In a conscious patient, titration of medications should occur through discussion with the patient. In an unconscious patient, signs of distress can include:

- restlessness
- diaphoresis
- hypertension
- tachycardia
- hyperventilation
- grimacing or vocalisation in response to nursing care.

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<sup>122</sup> M Mazer, C Allgood & Q Wu, 'The infusion of opioids during terminal withdrawal of mechanical ventilation in the medical intensive care unit', *Journal of Pain and Symptom Management*, vol. 42, 2011, pp. 44–51, [http://www.jpmsjournal.com/article/S0885-3924\(10\)01025-0/fulltext](http://www.jpmsjournal.com/article/S0885-3924(10)01025-0/fulltext).

### Case example

A 50-year-old male is day 3 after an out of hospital cardiac arrest with 45 minutes of CPR before return of spontaneous circulation. The patient has a GCS of 3/15 and is breathing spontaneously with an effective cough. Since admission he has exhibited severe repetitive myoclonic seizures that have been poorly responsive to anticonvulsant therapy. The seizures have been distressing to the family and have been managed with a propofol infusion of 250 mg/hr and 5 mg boluses of midazolam.

#### Issues:

- Seizures are distressing to the family and the care of the family would be a priority for the incapacitated patient.
- Higher doses of sedatives may accelerate the dying process through respiratory depression.
- Discussion with the local donor agency about the possibility of becoming a donor after circulatory death.

#### Resolution:

- Explanation to the family that the patient is deeply unconscious and the seizures are not distressing to him.
- Explanation to the family that control of the seizures is a priority to make the dying process as dignified as possible.
- The doctrine of the double effect ethically and legally allows the use of drugs to a level that may cause respiratory depression, since the control of the seizures allows a dignified dying process for the patient and ongoing care to the family. The intent is to avoid distress and preserve dignity rather than to cause death.
- After discussion with the local donor agency, it is agreed that donation after circulatory death is unlikely to be possible because of time from extubation to circulatory death.
- The patient is extubated on 250 mg/hr of propofol. One further seizure at extubation that is managed with 5 mg of midazolam. He dies four hours after extubation.

### 7.2.2.6 Palliative sedation

Occasionally patients on intensive care may be conscious prior to withdrawal of ventilatory supports. Examples of such patients would include a ventilated patient with end-stage motor neuron disease or a ventilator-dependent patient with a high spinal lesion. Optimal care of these patients could involve pre-emptive administration of anaesthetic or sedative drugs to unconsciousness, to avoid the suffering of awareness during the abrupt dying process.<sup>123</sup> Such palliative plans should always be discussed with the patient and family to achieve a consensus that allows the patient to have some

<sup>123</sup> SD Bruce, CC Hendrix & JH Gentry, 'Palliative sedation in end-of-life care', *Journal of Hospice and Palliative Nursing*, vol 8, 2006, pp. 320–327.

K McWilliams, PW Keeley & ET Waterhouse, 'Propofol for terminal sedation in palliative care: a systematic review', *Journal of Palliative Medicine*, vol. 13, 2010, pp. 73–76, <http://www.ncbi.nlm.nih.gov/pubmed/19827968>.

control in the dying process. The intent is always to avoid suffering that would be refractory to other means, rather than to hasten or cause death.

#### **Case example**

A 72-year-old male with recently diagnosed motor neurone disease presented with a respiratory arrest and is intubated by paramedics. He was admitted to ICU and his family gave a history of rapidly progressive bulbar and respiratory weakness. The next morning he is awake on the ventilator and breathing effectively on an inspiratory pressure support of 22cmH<sub>2</sub>O and 5cmH<sub>2</sub>O of peep, however he becomes acutely distressed and tachypnoeic with any reduction in pressure support. A family meeting is held at the bedside with the patient and his family and he clearly express that he does not want to pursue long-term respiratory support and accepts the terminal nature of his disease. He is also clear he does not want to die in distress and struggling for breath and would prefer to be comfortable with his family at his side.

#### **Issues:**

- The now fully conscious patient will likely deteriorate rapidly with distressing dyspnoea on withdrawal of mechanical ventilation.

#### **Resolution:**

- The family and patient are explained the process of slowly weaning the pressure support to extubation. The sedatives will be increased to maintain a respiratory rate of less than 20/minute and maintain patient comfort. It is likely that on extubation he will be unconscious and the intent of the sedatives is to maintain his comfort during the dying process.
- Morphine is started at 5 mg/hr and propofol at 50 mg/hr with small boluses of each. The pressure support is weaned by 2cmH<sub>2</sub>O to 8cmH<sub>2</sub>O over a period of five minutes. Any increase in respiratory rate above 20/minute or signs of distress are managed with further boluses of morphine and propofol. Extubation occurs at pressure support of 8cmH<sub>2</sub>O and 5cmH<sub>2</sub>O peep with the patient unconscious. He dies shortly after with his family at his side.

#### **ANZICS recommendation:**

In all cases, pharmacological treatments for symptom control at the end of life have the sole intention of relieving suffering in the patient dying. Medications should never be administered with the intention of hastening death.

#### **7.2.2.7 If death is not imminent**

Often death after withholding or withdrawal of supports is not imminent and the patient has minimal distress. Predicting time of death is often uncertain and families should be made aware of this. Pharmacological measures should always be available but may not be required. In such cases, non-pharmacological measures are important and there is an opportunity for family to spend time

with the patient before death. Cessation of intravenous fluids and medical feeding can be complex issues if death is not imminent and should be made by the teams involved, on a case-by-case basis. All patients should have the provision for oral sustenance, although it is usual for patients to reduce or refuse oral intake near the end of life.<sup>124</sup>

#### **7.2.2.8 Documenting the Palliative Care Plan**

When a decision is made to limit or withdraw treatment and implement a palliative approach in the ICU, it is recommended that the specific treatment decisions be documented, preferably in a standardised format that is unambiguous and recognised by the nursing staff. The Palliative Care Plan (see template in Appendix F) should stipulate which treatments should be continued, which should be discontinued and which palliative treatments should be added to the existing regimen. The treatment guidelines to the nursing staff should include timing and triggers for changing or discontinuing specific treatments.

#### **7.2.2.9 Site of death**

Good end-of-life care is something that all medical teams should be able to provide. Deaths that are likely to occur within a short timeframe are best managed in intensive care where the multidisciplinary team is familiar with the patient's and family's needs. In patients where the dying process is likely to be longer, transfer to an appropriate ward area under the admitting clinic or palliative care team is appropriate. At times it may be appropriate to consider enabling the patient to die at home. Clear communication with the family and effective medical and nursing handover is vital to ensure a smooth transition of care.

#### **7.2.3 Supporting the patient with their grief**

Do not forget grief in the dying ICU patient, if they are aware of their circumstances as they are approaching death. The ICU setting is unlikely to be their choice of place to die. They have lost autonomy, control over body functions, body image and mobility. They are not necessarily with the people they would choose. Supporting their needs is vital and should not just focus on physical needs. While communication may be very limited, your role in reassuring the patient of your commitment to their care, comfort and dignity is best spoken simply, compassionately and clearly with the patient. This communication can provide reassurance, reduce fearfulness and create opportunity for expression of their wishes. For many families to know this sensitive communication has occurred gives them relief and permission to have conversations in accordance with the dying circumstance. Frequently, the dying person is more aware than anyone of their situation. Their last wishes may range from a favourite drink or piece of music, to an unfinished conversation with an estranged family member or a last goodbye to a beloved.

When the person cannot speak for themselves, on the patient's behalf ask the family present if there are other significant people whom the dying person would have wanted present. Many families believe only blood relatives are permitted to attend critical care units. Ask them to think from the person's perspective, not their own. This is a time for inclusion of those nearest in relationship and affection to the patient including companions and treasured pets. This can take a critical care unit beyond its normal scope, but dying as a part of life calls for meaningful individualised care.

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<sup>124</sup> M Mazer, C Alligood & Q Wu, 'The infusion of opioids during terminal withdrawal of mechanical ventilation in the medical intensive care unit', *Journal of Pain and Symptom Management*, vol. 42, 2011, pp. 44–51, [http://www.jpmsjournal.com/article/S0885-3924\(10\)01025-0/fulltext](http://www.jpmsjournal.com/article/S0885-3924(10)01025-0/fulltext).

## 7.3 Care of the family

### 7.3.1 Care of the family during the dying process

Care of the family during the death of a loved one should occur through a multidisciplinary team approach that includes the nursing staff, social workers and pastoral or cultural leaders. The language used should emphasise the continuing care towards the patient and family.

Factors that may help families at this time include:

- a private family room close to the ICU
- assistance in organising accommodation
- enquiries about who wishes to be present and what assistance the hospital can provide to achieve this
- addressing of appropriate religious, spiritual and cultural needs
- open access to the patient's bed space
- help in explaining the situation to children.

Delaying withdrawal of treatment may be appropriate in order to wait for family members to arrive, however, any significant delay must be weighed against the ongoing burden of treatment that the patient is enduring.

Communicating with family members about what to expect and how they can be involved is a vital part of end-of-life care. Talking to their loved one and physical contact should be encouraged even when the patient is unconscious. Families should be made aware of how the treatments are to be withdrawn, the likely changes in the patient's condition, the likelihood of noisy breathing, an irregular breathing pattern and the unpredictability of when death will occur. They should be reassured that these features are normal in the dying process and that the patient is comfortable and not in distress. Families should be encouraged to communicate if they feel aspects of symptom control are inadequate. They may need reassurance about features of the dying process and that the patient is not aware or distressed by them. The bedside nurse will constantly monitor signs of distress and treat accordingly.

Occasionally family members will request escalation of medications in response to perceived distress in their loved one. Such requests should be followed by a reassessment of the patient symptoms and either reassurance that the features are not distressing or an escalation of palliative medications. Many signs of distress in a dying patient can be confusing and medications should never be withheld if there is a possibility of the patient being in distress.

### 7.3.2 Care of the family and significant others during grief and bereavement

Understanding grief and bereavement will help the ICU team to assist families to cope with death in the ICU. Grief is the psychological reaction experienced in anticipation of loss or after loss; it includes feelings and thoughts, social and physical reactions.

Grief changes over time. It is normal and its absence is abnormal, but it can be significantly delayed. It is a unique experience for each person depending on how they perceive the loss. Bereavement is

the state of having suffered a loss.<sup>125</sup> The cause of death, be it sudden and unexpected or the final chapter of a long and chronic illness, can influence the reactions of the family and needs for support. What can appear to ICU staff as an expected outcome is not necessarily the perspective of the family. The finality of death even after a long period of anticipatory grief can cause shock and intense emotions.

Grief reactions are many and varied, that is people do not all grieve in the same way. Children grieve differently from adults. Men grieve differently from women. Families may be critical of each other's reactions and ICU staff must be careful not to get caught up in this but to reassure of the normality of a spectrum of reactions. Strong emotional reactions are to be expected. Normal responses range from shock, distress, anger, fear, denial, guilt confusion and numbness. At extremes, the person is experiencing complete desolation and isolation. Supportive engagement affording time, validation of loss and grief can help patients and families express and work through these feelings. Use all the ICU team for support including social work and chaplaincy.

The inclusion and presence of children may be facilitated by the medical team and assisted by the social worker. Be sensitive, as no one knows these children better than their family. Children are frequently already aware that there is a major upheaval occurring in their world. Honesty and supportive inclusion of them in the hospital environment can be achieved through the team and family working together. It is important that families are aware children are welcome in critical care units. Discussion with parents can assist them in considering how to prepare children for the ICU setting. Age-appropriate care and language is essential with children. It is parents that children trust, so supporting parents at this time facilitates care of children.

If the staff know when children are likely to be visiting, they can prepare the environment and themselves. This can also reduce the likelihood of delayed visiting and protracted time in the waiting room. Staff can meet with the children pre- and post-visiting. Encourage families to have one adult to each child visiting as responses can be so varied and attention spans can be very different between children.

It is important not to stereotype cultures and religions. Seek translators early as they offer not only the means of crossing the spoken and written language division but also offer cultural insights to the families understanding of the health context, behaviours and beliefs in bereavement. Ask each family what is right for them spiritually and culturally through this time of dying and upon death. They can then guide the medical team as to their specific requests and needs.

Offering an inclusive invitation and welcome to the families' religious minister, priest or representative is appropriate to ensure the spiritual care of the patient and family is holistic. The Chaplain or social work staff can be of assistance in making this connection.

How the ICU team behaves after the patient has died can influence the grieving process for the family. Continued respectful care for the deceased and the family is vital. This can be challenging in a busy hospital environment and acknowledgement to the family of any potential for perceptions of disrespect needs to be addressed early. Care for this patient and family should remain a priority until all aspects of care have concluded.

Providing clear and prompt information about death and funeral procedures is helpful, as is explanation of any coronial procedures or requests for an elective post-mortem. At all times, the

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<sup>125</sup> TA Rando, *Grieving: how to go on living when someone you love dies*, Lexington Books, Lexington, 1988.

deceased person must be treated with dignity and respect. The ICU environment is not the familiar home environment. Every attempt should be made to provide a gentle and private space for grieving families. Help the family establish ways of relating to the deceased person, with private viewings, touch and hand prints and collection of locks of hair. It may be appropriate for family to help with cleaning the deceased person. Bereavement rituals, such as planning the funeral, are important acts of grieving. Careful and compassionate enquiry of the cultural needs and rituals the family may want to carry out, by the nurse or social worker or a pastoral care person who has an established relationship is a way of exploring these needs. This means the staff member will need dedicated time to focus on supporting the family.

The demand for the ICU bed has to be handled without contravening care for this now-deceased patient and their family. Abandonment of the family at this time will undo the respect and relationship it has taken time to develop. Check back with the family about anything the intensivists and the team can do to assist them.

Follow-up and contact numbers should be offered for assistance and for answering any questions but not necessarily for routine contact, which may be perceived as intrusive. Social work and pastoral care staff are best qualified to undertake this and can arrange a future interview with a senior medical staff member if needed. Do say goodbye to the family members. Intensivists have been a significant part of this end-of-life care for their family member and how intensivists close this communication with them is important.

### **7.3.3 Post-death follow-up care and referral**

Some bereaved families may be able to draw upon the care and support from each other and their social networks. Recognised risk factors surrounding death include sudden death, traumatic death, preventable death, death of a child, social isolation, past history of a mood disorder, recent other significant losses or previous history of prolonged grief reactions after any losses.

These situations can create more intense grief reactions and the importance of informed support can assist. It is individual and particular for each person. Society can be keen for 'closure' but grief is often a long and difficult journey with the first year being full of experiences without the presence of this family member at birthdays, anniversaries and special times of the year.

It is helpful to encourage family members to make contact with their family doctor as part of good bereavement care. The family doctor can provide support for physical health and emotional wellbeing. It is not unusual for health issues to present or seriously escalate during acute bereavement and additional resources or support may be needed, especially for the frail and elderly. In Australia, referral for additional counselling and psychological support can be assessed and supported by the treating GP through the Medicare Benefits Schedule, Better Access initiative.<sup>126</sup>

Grief and bereavement counselling and specific support groups can also be sourced through referral from the hospital social worker and chaplains. Many critical care units have booklets for families and friends after the death of a person in hospital. These can be facility specific and provide factual information for frequently asked questions, good guidance for self care through the early stages of loss and grief, plus contacts for assistance and counselling.

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<sup>126</sup> Australian Government, Department of Health, Medicare Benefits Schedule, *Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS (Better Access) initiative*, 2003, <http://www.health.gov.au/mentalhealth-betteraccess>.

A comprehensive follow-up bereavement aftercare service is provided in Australia by Donate Life through the Donor Family Support Coordinators in each state (see the Donate Life website<sup>127</sup> and in New Zealand, by Organ Donation New Zealand (ODNZ).<sup>128</sup> For more information about organ and tissue donation, see Chapter 10).

It can be important to leave an avenue open for family members to reconnect to the critical care staff if they are experiencing difficulties. The social worker and chaplain are often points of contact. Sometimes families need to come back to the ICU just to see the space or be in the environment because they feel a connection and have such strong visual memories. Sometimes these visits can be about meeting with senior ICU medical staff to review unresolved questions or about a need to review the person's memory of their time in ICU. If conflict was part of the end-of-life care, have another member of the team present, such as a colleague, social worker or senior nurse to assist in addressing any concerns.

The principles for good care of the dying patient and their families and supporting fellow ICU staff illustrates how important it is to work as a skilled multidisciplinary team in ICU. This can be one of the most rewarding and defining features of intensive care.

**ANZICS recommendation:**

Care of the family and significant others during the dying process and after bereavement is an integral part of intensive care. There should be a multidisciplinary approach with access to post-bereavement supports as required.

#### **7.4 Supporting the medical team**

Provision of treatment and care at end of life often involves complex clinical and ethical decisions. All members of the ICU team are vulnerable to emotional stress during this usually sad and often very disquieting time. The presence of conflict will increase the risk of adverse effects on healthcare workers. When the conflict is prolonged and involves legal intervention the risk is very high. Those directly involved are particularly at risk but do not ignore the potential for a death in ICU to affect staff who are not directly involved.

The emotional stress and distress for staff can be driven by their individual life experiences, ethical or religious viewpoints and uncertainties. Individual staff members closely involved with the patient and family can absorb the intensity of emotion and conflict that they observe. Caring for the patient and the many people involved such as partners, families, carers, and friends, can be emotionally exhausting. There is often little time for staff to process the death, the related events and recover as they move to care for the next critically ill patient coming through the doors. Anxiety can arise in staff who may feel a heightened sense of responsibility or uncertainty with regard to the patient's end-of-life care and expected death.

Support from the senior members of the ICU team is important, as is a supportive institution and positively engaged senior hospital management and executives.

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<sup>127</sup> Australian Government, Organ and Tissue Authority, <http://www.donatelife.gov.au/>.

<sup>128</sup> Organ Donation New Zealand, <http://www.donor.co.nz/>.

#### 7.4.1 Regular case discussions

Regular case discussion or opportunity for dialogue will help to create a team culture that is open, cohesive and resilient, particularly during a prolonged and conflicted end-of-life process. Case discussion and the airing of any questions and concerns early, during the time of treatment and after the person's death can facilitate trust in clinical judgement and processes. Such inclusive dialogue can build understanding of the endeavours of the medical team and in turn facilitate greater understanding and consistency of communication to the patient and family.

At case discussions, there is no wrong or right question but important concerns are opened up for non-judgemental dialogue. Senior staff can facilitate these sessions with appropriate experience such as the nurse in charge, ICU social worker, Head of Department, Liaison Psychiatry, chaplaincy and palliative care services. It can be more about the skilled person in each setting rather than a singular profession leading. Often co-facilitation of such sessions by medical staff with a senior inter-professional colleague can provide a sound balance for open communication. Such case conferences should be broadly inclusive and confidential. These requirements need to be clarified at the outset. Case discussions with the team can constructively focus on the facts of the patient's condition, what is going well, the challenges, the aims, lessons learned and 'where to from here' with respect to family communication.

Acknowledging the shared challenges and experience can build team cohesion and prevent teams from splitting through complex end-of-life situations.

#### 7.4.2 Other options to support staff

Separation of staff support from the family support may be appropriate in times of conflict. 'Off line' or individual confidential debriefing should be available for all ICU staff. Some health jurisdictions have confidential formal employee counselling services. Flexibility without coercion in the approach to staff support is important, as some ICU staff find the informal support of family, friends and peers more appropriate. It is important to talk with medical staff, junior and senior, to ascertain if they have support and to let them know that it is important to seek assistance if they are struggling. Remember this can be the intensivist – be prepared to seek the counsel of a colleague who will listen and have the capacity to provide assistance. No one is immune, or shielded by seniority or intellect, to the impact of emotional stress and distress.

In more difficult situations it may be appropriate to relieve the practitioner who is leading a prolonged conflict of their other clinical workload. This will allow them to focus on good communication and conflict resolution and appropriate rest intervals. The support of colleagues in maintaining this focus can be critical for that practitioner. Similarly, other core members of the ICU team who are providing ongoing support to a family where the end-of-life care has become one of conflict may need consideration of their clinical load and the support of their professional seniors and managers.

#### **ANZICS recommendation:**

The needs of the family of the dying patient and the needs of staff involved in end-of-life care in ICU should be recognised and specifically supported. The need for post-bereavement supports should be considered.

## Chapter 8 – Special situations and specific diagnoses

### 8.1 Overview

This chapter presents information about:

- end-of-life care in emergencies
- care after suicide attempts and refusal of treatment
- end-of-life care for people with respiratory conditions, motor neurone disease and post-coma unresponsiveness.

Although general principles of care apply to any specific situation, the following points are made regarding medical conditions or circumstances that may be relevant to intensive care practice.

### 8.2 End-of-life care in special situations

#### 8.2.1 End-of-life care in emergencies

In Australia and New Zealand, the requirement for consent for treatment is waived in an emergency. An emergency is defined as a situation where the patient is unable to give consent and the treatment is required immediately to:

- save the patient's life
- prevent serious injury
- prevent significant pain or distress.

The waiver of consent is limited. The only treatments permitted are those to achieve the goals listed above. If the treatment carries a risk of permanent disability, it is better to gain informed consent if this is possible in a reasonable time frame.<sup>129</sup>

The waiver of consent is set aside if the patient has a valid written Advance Care Directive that clearly refuses the treatment offered. Under these circumstances, there is an explicit refusal and emergency provisions do not apply, even if the patient may die and even if the family does not agree or accept the patient's directive.<sup>130</sup>

#### 8.2.2 End-of-life care after suicide attempts and treatment refusals

In New Zealand and Australia there are more than 2800 suicide deaths per year, which is almost twice the annual road toll. Suicide is a leading cause of death in younger age groups. For each completed suicide, it is estimated that there are approximately 30 attempts at suicide that often

<sup>129</sup> NSW Health, *Consent to medical treatment – patient information*, 2010, [http://www0.health.nsw.gov.au/policies/PD/2005/PD2005\\_406.html](http://www0.health.nsw.gov.au/policies/PD/2005/PD2005_406.html).

British Medical Association, *Consent tool kit*, <http://bma.org.uk/practical-support-at-work/ethics/consent-tool-kit>.

<sup>130</sup> *Hunter and New England Area Health Service v A* (2009) NSWSC 761, <http://www.lawlink.nsw.gov.au/scjudgetments/2009nswsc.nsf/6ccf7431c546464bca2570e6001a45d2/48dd2b1db7c8987dca257608000a28da?OpenDocument>.

require intensive care treatment.<sup>131</sup> Suicide is recognised as a major public health concern and the damaging effects of a suicide are felt throughout the family and more broadly in society. Common law recognises that society has an interest in preventing suicide.<sup>132</sup> Although suicide is not illegal itself, assisting suicide remains a criminal offence in all Australian jurisdictions.

Suicide attempts may be impulsive and a 'cry for help'. Treatment of the life-threatening attempt is generally effective, allowing for assessment and treatment of the underlying mental illness. Problems can occur for clinicians where the patient or substitute decision-maker has a written directive or verbally refuses lifesaving treatment in conjunction with a suicide attempt.

While many patients attempting suicide have mental illness, a significant proportion do not and may have concluded after much consideration that suicide is a rational solution to their situation, which may involve severe and progressive illness.

It is well established that patients with capacity have the right to refuse life-sustaining treatments. When patients have lost capacity, these choices are legally enforced through an Advance Care Directive.<sup>133</sup> This decision does not need to be well considered, agreed with by others or even have reasons attached. Patients suffering from mental illness who are suicidal do not necessarily lack capacity and may have given it considerable deliberation. Legislation in the states and territories, however, through the relevant Mental Health Acts,<sup>134</sup> allows detention and compulsory treatment of an individual suffering a mental illness (including treatment of the harms that have resulted from this illness) even if the person exhibits appropriate capacity. In the event a patient has no underlying mental illness, detention and emergency treatment should occur under common law in order to give time to assess the response to treatment and to further discuss with substitute decision-makers and healthcare providers what limitations of treatment are appropriate.

In cases of suicide or self-harm, the respect for an individual's autonomy in wishing to end their own life is outweighed by the broader negative impacts on the family and society whose interests also need to be respected.

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<sup>131</sup> Australian Bureau of Statistics, *National survey of mental health and wellbeing: summary of results, 2007*, cat.no. 4326.0, 2007, <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4326.0Main+Features12007?OpenDocument>. K McKenna & JE Harrison, 'Hospital separations due to injury and poisoning, Australia 2008–09,' Injury research and statistics series. No. 65. Cat. INJCAT 141. Canberra, ACT: Australian Institute of Health and Welfare. Accessed November 23, 2012 from <http://www.aihw.gov.au/publication-detail/?id=10737422893>.

Hunter Institute of Mental Health, 'Facts and stats about suicide in Australia,' Mindframe, National Media Initiative, 2014, <http://www.mindframe-media.info/for-media/reporting-suicide/facts-and-stats#sthash.xoV585Gf.dpuf>.

<sup>132</sup> S Callaghan & CJ Ryan, 'Refusing medical treatment after attempted suicide: Rethinking capacity and coercive treatment in light of the Kerrie Woollorton case', *Journal of Law and Medicine*, vol. 18, 2011, pp. 811–19, [http://www.academia.edu/1492917/Refusing\\_medical\\_treatment\\_after\\_attempted\\_suicide\\_Rethinking\\_capacity\\_and\\_coercive\\_treatment\\_in\\_light\\_of\\_the\\_Kerrie\\_Woollorton\\_case](http://www.academia.edu/1492917/Refusing_medical_treatment_after_attempted_suicide_Rethinking_capacity_and_coercive_treatment_in_light_of_the_Kerrie_Woollorton_case).

<sup>133</sup> *Hunter and New England Area Health Service v A* (2009) NSWSC 761, <http://www.lawlink.nsw.gov.au/scjudgments/2009nswsc.nsf/6ccf7431c546464bca2570e6001a45d2/48dd2b1db7c8987dca257608000a28da?OpenDocument>.

<sup>134</sup> *Mental Health (Treatment and Care) Act 1994* (ACT), [http://www.austlii.edu.au/au/legis/act/consol\\_act/mhaca1994274/](http://www.austlii.edu.au/au/legis/act/consol_act/mhaca1994274/).  
*Mental Health Act 2007 No 8* (NSW), [http://www.austlii.edu.au/au/legis/nsw/consol\\_act/mha2007128/](http://www.austlii.edu.au/au/legis/nsw/consol_act/mha2007128/).  
*Mental Health and Related Services Act* (NT), [http://www.austlii.edu.au/au/legis/nt/consol\\_act/mharsa294/](http://www.austlii.edu.au/au/legis/nt/consol_act/mharsa294/).  
*Mental Health Act 2000* (Qld), [http://www.austlii.edu.au/au/legis/qld/consol\\_act/mha2000128/](http://www.austlii.edu.au/au/legis/qld/consol_act/mha2000128/).  
*Mental Health Act 2009* (SA), [http://www.austlii.edu.au/au/legis/sa/consol\\_act/mha2009128/](http://www.austlii.edu.au/au/legis/sa/consol_act/mha2009128/).  
*Mental Health Act 2013 (No. 2 of 2013)* (Tas), [http://www.austlii.edu.au/au/legis/tas/num\\_act/mha20132o2013174/](http://www.austlii.edu.au/au/legis/tas/num_act/mha20132o2013174/).  
*Mental Health Act 2014 (No. 26 of 2014)* (Vic), [http://www.austlii.edu.au/au/legis/vic/num\\_act/mha201426o2014174/](http://www.austlii.edu.au/au/legis/vic/num_act/mha201426o2014174/).  
*Mental Health Act 1996* (WA), [http://www.austlii.edu.au/au/legis/wa/consol\\_act/mha1996128/](http://www.austlii.edu.au/au/legis/wa/consol_act/mha1996128/).

**Case example**

A 26-year-old female with bipolar disorder and previous suicide attempts presents having taken 100 g of lithium. She has with her an Advance Care Plan written six months previously, that states she does not wish to undergo any life-sustaining procedures in the event of a life-threatening condition and her priority is always to have a peaceful death without any invasive procedures. She also has a letter saying she has given her current situation much thought and feels her underlying mental illness is untreatable and wishes to die in peace. Her letter states she has taken a large overdose of lithium and has presented to hospital to allow her death to occur in a place with immediate access to palliative care so she does not die in any distress.

On examination she is drowsy and uncooperative but otherwise has a stable cardiorespiratory status. Her lithium level is 5.8 mmol/L and she is on chronic lithium therapy, her creatinine is raised at 170  $\mu\text{mol/L}$ . She refuse to answer any further questions and only says that she wishes to die peacefully.

She has been estranged from her family for many years and her next of kin is her partner who she has lived with for four years. He is contacted by phone but refuses to come into hospital. He states she has wanted to die for many years and has planned this event over the last two weeks. He confirms she does not want any lifesaving procedures and supports her in doing it in hospital with appropriate access to palliative care.

Her psychiatrist is contacted who says she has resistant bipolar disorder but he has not seen her for six months and her follow-up is with her GP. Her GP is called who says her last attendance was three weeks ago when she stated that she had little enjoyment in life but was not suicidal.

**Issues:**

- Patient has presented with an acute potentially fatal overdose where optimal therapy would involve dialysis and possible respiratory support. It would be anticipated that medical treatment would effectively manage the acute overdose.
- Her considered wishes over the previous two weeks are quite clear in that she does not wish dialysis or other invasive supports and wishes to die in peace. Her longstanding partner supports these wishes.
- Medical treatment of the overdose would go against her explicit Advance Care Plan.

**Resolution:**

- Medical consensus between the renal and medical team is that dialysis the most appropriate medical management.
- Discussions with her psychiatrist and GP concur that she should be detained under the mental health act and receive all lifesaving medical treatments.
- She is dialysed and ventilated after a seizure but subsequently improves to be discharged under the care of psychiatry within 72 hours.

**ANZICS recommendation:**

In all suicides attempts aggressive treatment should be instituted in the emergency situation under the provision of the Mental Health Acts or common law.

**8.2.3 Treatment limitation in conjunction with suicide**

After suicide attempts, it is not uncommon for life-sustaining therapy to be withdrawn or withheld. After attempted hangings, patients will often present with a severe hypoxic brain injury and therapy is withdrawn where it is agreed that ongoing treatment is not in the patient's best interests. This assessment is made based on the extent of the brain injury rather than the intent of the patient to end their own life. This is not to say that the extent of any mental illness is not relevant to such decisions. Like all comorbidities, the extent of mental illness has relevance to how aggressively life-sustaining treatments are pursued. All such decisions will be made in conjunction with the substitute decision-maker and it may be useful to ask the following question: 'Would it be reasonable to withdraw active treatments given the clinical circumstance, if it were not an attempted suicide?'

### Case example

A 48-year-old man was seen to run into the path of a van travelling at 80 km/hr. At the scene he had a tension pneumothorax decompressed, a heart rate of 122 and a BP of 100/70 with cool peripheries and a GCS of 8/15 (E1 M5 V2). He was placed in a rigid collar and pelvic binder for transfer to the emergency department.

In the ED his saturations were 94%, his heart rate 52 with a BP of 60 systolic and a GCS of 7/15 (E1 M5 V1). He was transfused with four units of blood and four units of FFP, his cardiovascular state improved and his arterial lactate fell from 12 to 4 mmol/L.

A trauma CT showed a normal CT head, fractures of transverse processes C7, T1 and T2 with a right subclavian artery disruption. He had multiple rib fractures, a sternal fracture with bilateral pneumothoraces and subcutaneous emphysema, and the aortogram showed only the right subclavian injury. The CT abdomen /pelvis showed no intra-abdominal injury with bilateral pubic rami fractures and sacral fractures with a retroperitoneal haematoma, he also had an open right knee wound with a tibial fracture.

He had bilateral chest drains inserted, the right subclavian injury was stented and flow returned to the arm, his tibial fracture was washed out and fixed then he was admitted to ICU. After a further transfusion and low dose inotropes, his condition stabilised and on a low dose morphine infusion and was able to follow simple commands.

Old notes revealed a history of Huntingdon's disease, which was diagnosed eight years previously. He had seen a neurologist at age 40 and said quite lucidly '*one day I will go out on a fishing boat and not come back*'. He had subsequently separated from his wife and children and had become increasingly disabled although still lived alone. He had recently seen a psychiatrist for agitation and psychotic depression although had not been taking his medication.

#### Issues:

- A clear suicide attempt has result in severe but likely survivable injuries.
- Ongoing aggressive medical management would involve a likely prolonged ICU stay with significant associated burdens and almost certainly a discharge to a permanent care facility.
- He has concurrent irreversible underlying conditions that will impact his recovery and rehabilitation.

#### Resolution:

- Discussions occur between the intensivist, surgeon, patient's family, psychiatrist and neurologist who all agree that continuing intensive treatment is not in his best interests.
- He is weaned from respiratory support on a morphine infusion and the inotropes are stopped. He is extubated to room air and dies five hours later.
- His death is referred to the Coroner.

**ANZICS recommendation:**

Treatment limitations in conjunction with suicide are reasonable based upon the prognosis, comorbid conditions (including mental illness if present) and a consensus decision about the patient's best interests. It is important to consult widely about such decisions including, the substitute decision-makers and other health professionals who have known the patient prior to the self-harm.

### 8.3 End-of-life care for specific diagnoses

#### 8.3.1 Respiratory conditions

Patients with advanced respiratory illnesses, such as chronic obstructive pulmonary disease (COPD), are generally at risk of acute exacerbations and sudden deterioration that may result in being admitted to an ICU for mechanical ventilation and other support. For the most part, at the time of admission it would be expected that the person will either improve with treatment and be discharged alive or there will have been discussion and treatment planning outlining the course of action if there is no clinical improvement or if there is a deterioration.

Managing these patients, especially those with advanced COPD, often present some specific challenges.

In patients with severe COPD it may be difficult to determine the prognosis in the individual patient and, specifically, the likelihood of death occurring during the current admission. There are several factors which are associated with poor prognosis, including very poor lung function, exercise tolerance and functional state, low body mass index, use of domiciliary oxygen, presence of comorbidities, and frequency of previous admissions for exacerbations of COPD. However, research has also shown that:

- 60% of patients with severe COPD who are intubated survive hospital admission and many return to an acceptable level of function and quality of life
- median survival after an ICU admission for COPD is two years
- in an Australian study of patients with COPD who required prolonged weaning via a tracheostomy in a ward-based weaning unit, 78% were successfully weaned and 43% were still alive at 12 months.<sup>135</sup>

Ideally, patients with COPD and other advanced respiratory disease would have a good understanding of their disease trajectory, which typically follows a course of gradual decline punctuated by acute exacerbations and recovery, and will have undertaken advance care planning. Unfortunately for many patients this is not the case, despite evidence showing that patients and their families want this information and want to participate in advance care planning.

There are many reasons suggested as to why this is lacking, but the main determinant likely relates to the uncertainty of prognosis, tied with the slowly progressive nature of the disease and the

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<sup>135</sup> LM Hannan, S Tan, K Hopkinson et al., 'Inpatient and long-term outcomes of individuals admitted for weaning from mechanical ventilation at a specialized ventilation weaning unit', *Respirology*, vol. 18, 2013, pp. 154–160, <http://onlinelibrary.wiley.com/doi/10.1111/j.1440-1843.2012.02266.x/full>.

difficulties doctors and other health care workers have in deciding when to and how to conduct advance care planning in these patients. Furthermore, even when a patient participates in advance care planning, they often opt for a 'trial of treatment' without clear guidance as to how decisions to stop treatment should occur. Healthcare professionals may be fearful that these discussions take away a patient's hope, and yet evidence suggests patients find these conversations helpful, allowing them to regain some sense of control. These conversations can be further facilitated by talking in terms of 'hoping for the best, while planning for the worst'.

Patients with advanced respiratory disease often have high levels of anxiety, depression and a heightened fear of breathlessness. These factors may hamper efforts to wean patients from ventilation and to extubate them, and may also affect the ease and success of utilising non-invasive ventilation. In addition, family members of these patients also often experience anxiety and depression, which may further complicate the situation. It is also not uncommon for the family to have previously been informed that the prognosis was poor, or that death was likely, only to find that the patient recovered and was discharged to live for a further period. As a result of these experiences, patients and family may struggle to accept and trust the information doctors provide during episodes of deterioration.

### **8.3.2 Motor neurone disease**

People with motor neurone disease (MND) usually die from hypoventilatory respiratory failure due to progressive respiratory muscle weakness, with patients also at risk of aspiration and pneumonia due to bulbar muscle involvement and poor cough. Most patients are aware of the poor prognosis, retain their cognition even late in the disease, and often have formal or informal advance care planning. The most significant advance in MND care over recent years has been provision of domiciliary non-invasive ventilation that is associated with improved quality of life and survival.

For the most part, people with MND elect not to have invasive ventilation. The main reasons for this decision relate to:

- the ongoing progressive nature of the disease with subsequent deterioration in quality of life
- the significant resources (from both care systems and family) required to provide care in such a situation
- the likelihood of either becoming 'locked in' and unable to express treatment preferences or concerns, or having to make a future decision to have treatment withdrawn.

These situations are emotionally very difficult for the person with MND and their family, and most people prefer to avoid these.

There are, however, two scenarios where a person with MND may receive invasive ventilation, and where subsequent decisions regarding either the withdrawal of treatment or the continuation of invasive ventilation with a view to attempted weaning are required. Studies show weaning success is less than 50%, and even if successful most patients require non-invasive ventilation.

The first situation where this may occur is in the person with diagnosed MND who has not participated in advance care planning, and who then has an acute severe chest infection or other illness resulting in respiratory failure, and has invasive ventilation commenced. The other scenario is when a person develops respiratory failure prior to a diagnosis of MND.

### 8.3.3 Post-coma unresponsiveness

Post-coma unresponsiveness (PCU), formerly referred to as persistent vegetative state (PVS) and minimally responsive state, are states of severe brain injury on a continuum.

The Australian National Health and Medical Research Council (NHMRC) has produced three documents on PCU including a Clinical Framework for Diagnosis,<sup>136</sup> Ethical Guidelines for Care<sup>137</sup> and A Guide for Families and Carers.<sup>138</sup>

These documents are very detailed, and should be consulted by intensivists in Australia and New Zealand early in the course of managing a patient who may develop one of these conditions.

Important considerations for intensivists include:

- The term PCU should only be used to describe patients who have reached at least four weeks after the onset of post-coma eye-opening, and who meet the criteria described in the Framework for Diagnosis. Use of this term (or the more common 'PVS') outside strict criteria is confusing, and has led to legal complications in New South Wales.
- Although there is widespread public fear of this devastating neurological condition (and it receives special mention in Advance Care Directives prepared by the Law Society), each case must be treated individually, with due regard to the care required by these highly dependent patients.
- An ethical conundrum arises when we try to establish the best interests of a patient who appears to have no appreciable interests. All the usual criteria for end-of-life decision-making apply, including honouring the advance wishes of the patient, and/or working with substitute decision-makers to determine a reasonable care plan.
- Artificial nutrition and hydration are medical treatments according to a number of legal decisions in Australia and elsewhere and, therefore, can be discontinued like any other medical treatment.
- The doctrine of sanctity of life has proved divisive in some high-profile cases of PCU overseas, but this results from a misunderstanding of the doctrine, and confusion with the more extreme notion of vitalism. The NHMRC guidelines make it clear that 'the question is not whether the patient's life is worthwhile, but whether a treatment is worthwhile'.

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<sup>136</sup> National Health and Medical Research Council, *Post-Coma Unresponsiveness (Vegetative State): A Clinical Framework for Diagnosis. An Information Paper*, 2003, <http://www.nhmrc.gov.au/guidelines/publications/hpr23>.

<sup>137</sup> National Health and Medical Research Council, *Ethical guidelines for the care of people in post-coma unresponsiveness (vegetative state) or a minimally responsive state*, 2008, <https://www.nhmrc.gov.au/guidelines/publications/e81-e82>.

<sup>138</sup> National Health and Medical Research Council, *Post-coma unresponsiveness and minimally responsive state – A guide for families and carers of people with profound brain damage*, 2008, <https://www.nhmrc.gov.au/guidelines/publications/e81-e82>.

## Chapter 9 – Infants and children

### 9.1 Overview

This chapter presents information about:

- issues to consider during end-of-life care of infants and children
- standards for end-of-life decision-making for infants and children
- the role of the parents in end-of-life decision-making
- prognosis and end-of-life decision-making
- practical suggestion for intensivists providing end-of-life care for infants and children.

It should be acknowledged from the outset that to many in our society, the death of a child seems to violate the natural order of how things should be. As such, a child's death has the potential to lead to the child's family, and the intensivist, questioning the meaning of life, their faith in religious beliefs and morality generally. This has not always been so, and the increase in these beliefs follows steep declines in the childhood mortality rates in more developed countries over the past century.<sup>139</sup>

Most children dying in hospitals now do so following an active decision to withdraw or limit life-sustaining treatment,<sup>140</sup> so it is important to consider the decision-making process and planning in this context.

### 9.2 Issues for end-of-life care decision-making for infants and children

#### Case example

An 18-month-old child has an undiagnosed metabolic disorder characterised by severe developmental delay, refractory seizures and microcephaly. He has had recurrent hospital admissions with status epilepticus and aspiration pneumonia, including several previous admissions to intensive care. On this occasion, he presents to the emergency department with respiratory distress and evidence of poor perfusion. He has septic shock and respiratory failure. The emergency consultant talks with the ICU team, as it appears that the infant may need intubation. Several clinicians who know the child from previous admissions express the view that admission to intensive care would not be in the child's interests, while others argue that given uncertainty about his underlying diagnosis, treatment must be provided. His parents are anxious and distressed, and ask the intensivist what she would recommend.

<sup>139</sup> RK Basu, 'End-of-life care in pediatrics: ethics, controversies, and optimizing the quality of death', *Pediatric Clinics of North America* vol. 60, 2013, pp. 725–39, <http://www.ncbi.nlm.nih.gov/pubmed/23639665>.

<sup>140</sup> P Moore, I Kerridge, J Gillis et al., 'Withdrawal and limitation of life-sustaining treatments in a paediatric intensive care unit and review of the literature', *Journal of Paediatrics and Child Health*, vol. 44, 2008, pp. 404–8, <http://www.ncbi.nlm.nih.gov/pubmed/18638332>.

Z Stark, J Hynson & M Forrester, 'Discussing withholding and withdrawing of life-sustaining medical treatment in paediatric inpatients: Audit of current practice', *Journal of Paediatrics and Child Health*, vol. 44, 2008, pp. 399–403, <http://www.ncbi.nlm.nih.gov/pubmed/18638331>.

**Issues:**

- Should decisions to limit treatment for infants and children be based on different standards than those for adults?
- What is the role of parents in decision-making for children and infants?
- How certain must intensivists be about the prognosis, and is there any room for hope?
- Under what circumstances is it ethical to limit or withdraw life-sustaining treatment?
- How should intensivists answer the question: ‘What would you do if this were your child?’

**Resolution:**

- Decisions to limit treatment for infants and children are based on a similar standard to adults, namely, that the burden of treatment is judged to outweigh the benefit provided. Adults have usually had the capacity to express values and preferences surrounding how they wish to live (and sometimes die) whereas infants and children have not, so the decision is usually based on the best interests test.
- The child’s parents can usually be relied upon to make decisions in accordance with the child’s best interests, although this is not invariably the case.
- There is usually some uncertainty regarding prognosis, but we must be as certain as it is possible to be when providing the parents with a prognosis on which to base their decision-making.
- It is ethical to limit or withdraw life-sustaining treatment when it is not in the child’s best interest to receive the treatment.

Intensivists may sometimes be asked by parents, ‘What would you do if this were your child?’ On the one hand, answering this question honestly may improve trust in the relationship with the parents and should not be merely sidestepped. On the other hand, intensivists may not share the values and beliefs of their patient and families and, therefore, should be careful to avoid unfairly influencing or even coercing the parents. It is, therefore, worth considering how to respond prior to talking to the parents, and attempt to determine what they are seeking by asking the intensivist the question. Further reading is available.<sup>141</sup>

**9.2.1 Should decisions to limit treatment for children or infants be based on different standards than those for adults?**

Fundamental ethical questions around life-sustaining treatment for infants and children are the same as they are for adults.

The key difference is that for infants and, perhaps to a lesser extent, older children, we usually do not have evidence of their own views or wishes about treatment. Therefore decisions are based largely on the ethical principles of beneficence and non-maleficence. Clinicians, as well as parents and carers, are morally and legally obliged to always act in a child’s best interests. This process often

<sup>141</sup> RD Truog, “Doctor, if this were your child, what would you do?”, *Pediatrics*, vol. 103, 1999, pp. 153–155, <http://pediatrics.aappublications.org/content/103/1/153.extract>.

R Mannix, ‘A piece of my mind. What would you do, doctor?’, *JAMA*, vol. 311, 2014, pp. 911–912, <http://www.ncbi.nlm.nih.gov/pubmed/24595772>.

LF Ross, ‘Why “doctor, if this were your child, what would you do?” deserves an answer’, *The Journal of Clinical Ethics*, vol. 14, 2003, pp. 59–62, <http://www.ncbi.nlm.nih.gov/pubmed/12953354>.

J Halpern, ‘Responding to the need behind the question “Doctor, if this were your child, what would you do?”’, *The Journal of Clinical Ethics*, vol. 14, 2003, pp. 71–78, <http://www.ncbi.nlm.nih.gov/pubmed/14628810>.

involves weighing up the potential benefits and burdens of different treatment options, for example, providing invasive life-sustaining treatment versus palliative care. In practice, this balancing often involves judgements based on values, and it can be very difficult to know for certain what would be in a child's best interests. Views may differ among families and clinicians as well as among clinicians.

### **9.2.2 What is the role of parents in decision-making for children and infants?**

While families are important for end-of-life decisions for most patients, they are central in making decisions for children. Parents will usually be keen to exercise their 'parental autonomy' to decide what is best for their child. Parents also provide important information about the child's previous health state and response to treatment. They also have an important role in weighing up the benefits and burdens of further treatment. Although parents will try to do what is best for their child, their views about whether or not treatment is in a child's best interests may sometimes differ from those of others involved in the child's care.

In cases where a child is under the care of the state, it is the responsible Minister (or his delegate) who has legal responsibility to provide consent for medical procedures. A child's biological parents may still be involved in decision-making in some circumstances.

Children's capacity to make decisions evolves over time. Older children and adolescents may have considerable experience of medical treatment, including of previous intensive care stays. The views of the child are important, and there should be a presumption that children are involved in decisions where it is possible to do so, and to a degree that reflects their ability and understanding.

Although parents have a central role in paediatric decision-making, they will not always make decisions by themselves. Some families may be unable or unwilling to make decisions, and prefer that doctors make final decisions about continuation or limitation of life-sustaining treatment. Most parents, though, do wish to be involved in decisions.<sup>142</sup> A shared approach to decisions is often appropriate, with health professionals and parents deliberating together on what course of treatment would be best for a child.<sup>143</sup>

### **9.2.3 How certain must intensivists be about the prognosis?**

Providing accurate information regarding a patient's expected prognosis is essential to allow any decision-making process to be truly 'informed'. Apart from where brain death has occurred, however, intensivists can rarely be 100% certain surrounding prognosis and there will always be a degree of uncertainty. Intensivists can, and should, however, be expected to be 'as certain as we can possibly be' in any particular situation.<sup>144</sup> Establishing a consensus view among colleagues, seeking a second opinion, and obtaining input from experts such as neurologists are all often helpful steps to ensure that an honest and balanced prognosis is provided to the parents. Where uncertainty exists with regard to the value of a treatment, the parents' values and views play an important role in determining whether or not it ought to be given, provided they have been informed about all potential benefits/burdens of the treatment.

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<sup>142</sup> J Sullivan, P Monagle & L Gillam, 'What parents want from doctors in end-of-life decision-making for children', *Archives of Disease in Childhood*, vol. 99, 2014, pp. 216–20, <http://www.ncbi.nlm.nih.gov/pubmed/24311188>.

<sup>143</sup> R Drake, E Ball, N Cheng, et al., *Decision-making at the end of life in infants, children and adolescents*, Royal Australasian College of Physicians, 2008.

<sup>144</sup> J Gillis & B Tobin. 'How certain are you, doctor?' *Pediatric Critical Care Medicine*, vol. 12, 2011, pp. 71–2, <http://www.ncbi.nlm.nih.gov/pubmed/20495506>.

When discussing prognosis with the parents it is often helpful to explicitly outline the expected future outlook for their child, including limitations on ‘activities of daily living’ such as the ability to communicate, self care, sit and walk independently, etc., in addition to any anticipated cognitive limitations. This may help them to make a decision regarding what they would – and would not – consider to be a ‘tolerable burden’ for their child to bear in the future. Building trust depends on presenting an honest and realistic outlook.

#### **9.2.4 Under what circumstances is it ethical to limit or withdraw life-sustaining treatment?**

End-of-life decision-making involves profound life and death decisions, and the deliberation process for all involved must be ethically rigorous and robust. ‘Compassion fatigue’ and caregiver frustration are not legitimate reasons to stop treatment. It is essential that both the family and the caregivers are clear in their own minds why limitation or withdrawal of life-sustaining treatment might be justified in a particular situation and are clear that they do not feel ‘morally compromised’ in any way.

It is important to emphasise that life-sustaining treatment is not withdrawn *in order that the patient dies*, but rather, the treatment is withdrawn because it is not felt to be in the child’s best interests to continue to provide the treatment. Intensivists should not impose treatment that is not judged to be medically indicated. While the death of the child might be foreseeable, it must not be the intent of the withdrawal of the medical treatment.

The Royal College of Paediatrics and Child Health (UK) recently categorised such situations in their publication ‘Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A framework for practice’.<sup>145</sup> Situations where withholding/withdrawal of life-sustaining treatment may be considered generally should fall into one or more of the following categories:

- a) The patient has a life-limiting illness and is likely to die in spite of treatment

This might include circumstance where the patient continues to deteriorate despite escalating invasive treatment and cure is unlikely. In the event the child has a cardiac arrest, resuscitation is unlikely to provide any benefit. The potential benefit of prolonging life by a matter of hours to days is outweighed by the burden imposed, and withdrawal of life-sustaining treatment and provision of palliative care is justified.

- b) The patient is unlikely to gain benefit from the treatment even if it may prolong life

In other situations, children may, due to either pre-existing or newly-acquired impairments, be unable or unlikely to gain benefits from treatment, even if treatment may prolong life. Decision-making in this context involves a careful balancing of the burdens imposed by ongoing or proposed treatment against the likely benefits, and the values attributed to those benefits. A child with severe neuromuscular disease may be kept alive by prolonged mechanical ventilation via a tracheostomy, but be totally immobile, aphasic, and entirely dependent on others for all activities of daily living. Although opinions may vary, many would consider that the benefits of treatment in this example do not outweigh the combined burdens of the disease and treatment, and that adopting a palliative approach would be in the child’s best interests. Similarly a child in a post-coma unresponsive state (previously known as

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<sup>145</sup> V Larcher, D Wilkinson, J Brierley et al., Making Decisions to limit treatment in life limiting and life-threatening conditions in children: a framework for practice. Royal College of Paediatrics and Child Health (UK), in press.

a persistent vegetative state) may lack sufficient awareness to gain any demonstrable benefit from life, so that anything that imposed even a minimal burden (even artificial feeding) might be considered excessive. In such a case, withdrawal would be both ethically justifiable<sup>146</sup> and lawful.<sup>147</sup>

c) An older child has had input into the decision-making process

In rare cases an older child may be considered mature enough to have 'capacity', and might be able to have input into the end-of-life decision-making process. This would generally only occur where there was consensus among others involved in the process (parents and clinicians) that ongoing treatment or withholding/withdrawal of treatment were both acceptable options in the circumstance.

### 9.2.5 Achieving consensus in end-of-life care decision for infants and children

The patient's co-consultants, social workers, nurses and intensivists involved in the child's care should meet separately prior to meeting the family. This meeting provides an opportunity to discuss the likely prognosis and decide which therapeutic options would be considered appropriate in the circumstances. The nurses and social worker will often be able to provide insight into the family's views. Consensus should be reached among the team prior to any meeting with the family. If consensus cannot be reached there should be an agreed strategy formulated to address any uncertainties or differences of opinion within the team (see also Chapter 6, section 6.2.1). While differences of opinion regarding the preferred treatment options are not uncommon, often based on individual clinician values or approach, the family should not be left with the sense that the team caring for their child is racked with division and uncertainty, and ideally a 'united front' should be presented. A plan for how the family meeting will be conducted, what topics will be covered, and what options will be presented should be enunciated in advance.

The family must be assured that any change in the focus of the care provided from treatment to comfort does not represent giving up or abandonment<sup>148</sup> and that the team will continue to provide excellent care for their child.

### 9.2.6 What if consensus cannot be reached?

Sometimes parents and health professionals reach different conclusions about treatment for a child. Parents can usually be relied upon to do what they feel is best for their child. However, it is not always appropriate or necessary to follow parents' requests.

When the medical team agrees that life-sustaining treatment clearly benefits a child, it should be provided even if the parents disagree. If there is a high risk of substantial harm to a child from treatment, without corresponding benefit, it should usually not be provided, even if parents strongly

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<sup>146</sup> LJ Nelson, CH Ruston, RE Cranford RE et al., 'Forgoing medically provided nutrition and hydration in pediatric patients', *The Journal of Law, Medicine & Ethics*, vol. 23, 1995, pp. 33–46, <http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.1995.tb01328.x/abstract>.

<sup>147</sup> Ashby MA & Mendelson D, 'Gardner; re BWV: Victorian Supreme Court makes landmark Australian ruling on tube feeding', *Medical Journal of Australia*, vol. 181: 2004, pp. 442–5, <https://www.mja.com.au/journal/2004/181/8/gardner-re-bwv-victorian-supreme-court-makes-landmark-australian-ruling-tube>.

*Airedale Hospital Trustees v Bland* (1992) UKHL 5 (04 February 1993), <http://www.bailii.org/cgi-bin/markup.cgi?doc=/uk/cases/UKHL/1992/5.html&query=bland&method=boolean>.

<sup>148</sup> J Gillis, 'We want everything done', *Archives of Disease in Childhood*, vol. 93, 2008, pp. 192–3, <http://www.ncbi.nlm.nih.gov/pubmed/18319382>.

desire it. The clinicians must remain true to their own conscience and should feel confident that they cannot be forced to administer treatment they consider ‘unconscionable’.

There are some cases (for example, neonatal (type 1) Spinal Muscular Atrophy) where opinions may vary (locally, nationally and internationally) regarding the appropriateness of providing ongoing treatment<sup>149</sup> and consultation with experienced colleagues is recommended in such situations.

The basic approach to resolving these differences about treatment is the same for children as for adults, and may involve mediation, second opinions, ethics consultation and/or legal review. Rarely, cases may be decided only after referral to the court. Most disagreements, however, can usually be resolved by ongoing discussion, consultation, time and more time (see Chapter 6).

### 9.2.7 Use of the term ‘quality of life’

It is becoming apparent that use of the term ‘quality of life’ may be unhelpful due to its essentially subjective nature, and indeed, parents may find clinicians making a judgement regarding the ‘quality’ of their child’s life offensive. On the other hand, it is our duty to conscientiously try to determine ‘the benefits of life’, including, for example, the amount of pleasure a child is likely to experience from life, and weigh these perceived benefits against the burdens of ongoing treatments. The outcome of this ‘balancing act’ should inform decisions about whether a treatment is likely to be of further benefit or not, but use of the terms ‘quality of life’ (and ‘futility’) are probably best avoided wherever possible (for more on the use of language, see Chapter 5).

### 9.2.8 Use of the terms DNR, NFR or AND

Many centres may prefer to use the term ‘allow a natural death’ (AND),<sup>150</sup> as the term may be considered more accurate and may avoid giving the impression that something potentially beneficial is being withheld from the patient. Not all agree though<sup>151</sup> and ‘do not resuscitate’ (DNR) and ‘not for resuscitation’ (NFR) may still be widely used.

Whatever term is used, it is essential that a discussion takes place with the parents concerning which specific interventions are and are not appropriate in the circumstance based on an analysis of ‘benefits versus burden’. This should include a detailed discussion regarding interventions such as nasogastric feeding, endotracheal intubation, non-invasive bag mask ventilation, superficial and deep suctioning, intravenous access, vasoactive drugs, antibiotics, etc.

The outcome of these discussions should be communicated to other team members as well as clearly documented in the patient’s notes or on a specifically designed form. The information should be readily accessible to ensure that clinicians caring for the child overnight, for example, immediately know what interventions are considered appropriate and which are not.

Advanced Care Directives have less relevance in paediatric practice compared with adult practice as:

- children do not usually have the capacity to communicate their future treatment choices

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<sup>149</sup> M Hardart & R Truog, ‘Spinal muscular atrophy–type I’, *Archives of Disease in Childhood*, vol. 88, 2003, pp. 848–50, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1719334/>.

MM Ryan, H Kilham, S Jacobe et al., ‘Spinal muscular atrophy type 1: Is long-term mechanical ventilation ethical?’ *Journal of Paediatrics and Child Health*, vol. 43, 2007, pp. 237–42, <http://www.ncbi.nlm.nih.gov/pubmed/17444824>.

<sup>150</sup> S Venneman, P Narnor-Harris, M Perish & M Hamilton. “‘Allow natural death’ versus “do not resuscitate”: three words that can change a life’, *Journal of Medical Ethics*, vol. 34, 2008, pp. 2–6, <http://www.ncbi.nlm.nih.gov/pubmed/18156510>.

<sup>151</sup> YY Chen & SJ Youngner, “‘Allow natural death’ is not equivalent to “do not resuscitate”: a response’, *Journal of Medical Ethics*, vol. 34, 2008, pp. 887–8, <http://www.ncbi.nlm.nih.gov/pubmed/19065754>.

- their substitute decision-makers are usually the parents and they are almost always present when treatment decisions need to be made.

On the other hand, many children do suffer from chronic, life-limiting illnesses and for these children a reasoned discussion in the cold light of day with the child's regular physician to explore what the parents/guardians and child might consider reasonable future treatment options is helpful. Documentation of the outcome of such discussions will also provide helpful information to an ambulance crew or emergency department staff if a child has agreed treatment limitations or even palliative care at home needs urgent transfer to hospital.

### **9.3 Practicalities at the end of life of infants and children**

#### **9.3.1 Supporting parents during withdrawal of life-sustaining treatment**

It is helpful to inform the parents what to expect following the withdrawal of life-sustaining treatment. If their child is to be extubated, find out whether the parents want this to happen while they are cuddling their child or with their child on the bed. Additionally, they should be given the opportunity to continue their role of 'caring parent' (they do not usually stop their parent role even while their baby/child is dying) and to be involved in their child's care. A single room should be provided wherever possible, and visiting restrictions for other family members and friends liberalised. Some parents may wish to hold their child, lie in the bed with her or him or in a bed close by. Prepare them for the possibility that their baby or child may develop a gasping breathing pattern shortly before death (agonal gasping). Many parents find this very distressing, and it is important to reassure them that this is not a sign of pain or distress. They should be assured that adequate analgesia and sedation will be provided as necessary to alleviate any apparent distress, but also informed that nothing will be done (nor can anything be done lawfully!) to 'speed up' the dying process.

Many parents may find themselves focusing on the monitor screens rather than their child at the end of life, and generally monitoring should cease. If any monitoring is considered necessary, this can usually be done remotely.

There should usually be no rush to formally declare death, and many children will have a (slow) heartbeat for a considerable period of time following extubation. It is important, of course, that this is done at some time and the time of death must be properly documented.

#### **9.3.2 Practical support for parents around the time of death of their child**

Whether sudden or expected, the death of a child is one of the most profound and terrible tragedy that a parent will ever experience. Wherever possible, parents and families should be provided with sufficient time (and space) to say goodbye to their child. Additionally, they should be given the opportunity to resume their role of 'caring parent' and become involved in their child's cares if at all possible.<sup>152</sup> A single room should be provided wherever possible, and visiting restrictions liberalised as felt appropriate. Some parents may wish to hold their child or even lay in the bed next to them, and this should be allowed within the bounds of acceptable safety. It may be possible, in some circumstances, for parents to take their baby or child out of the hospital after death.

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<sup>152</sup> SA McGraw, RD Truog, MZ Solomon, et al., "I was able to still be her mom" Parenting at end of life in the PICU', *Pediatric Critical Care Medicine*, vol. 13, 2012, e350–e356, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3475764/>.

The story surrounding their child's death becomes part of the family history, and is likely to be retold (replayed) throughout the lives of the parents, siblings and grandparents. It is important to provide sufficient information to the family to assist them to build up a narrative around the death that may help their adjustment in the future.

Many parents are too shocked and distressed to think about creating mementos at the time of loss. In most units, staff are very good at producing and collecting mementos such as hand and footprints and samples of hair. 'Heartfelt' is an Australia-wide volunteer organisation of professional photographers who take photos of terminally ill infants and children as a gift to their families.

The family must be assured that their child will not be abandoned, and that the team will continue to care for their beloved child, albeit with different goals. Many parents find that repeated affirmation of the decision to refocus the goals of care helpful.<sup>153</sup>

### 9.3.3 Legal issues

See also Chapter 2.

### 9.3.4 Coronial cases

Usually one can anticipate in advance whether the death of a child will need to be referred to the Coroner, and this aspect may influence the end-of-life care. Depending on the jurisdiction, as well as the individual circumstances of a case, a Coroner may insist that all tubes and infusions remain *in situ* following death. In such circumstances it may be worthwhile speaking directly with the Coroner's Forensic Pathologist who will often give permission to remove the endotracheal tube once reassured that the correct positioning has been confirmed clinically. The Coroner's Office will usually agree to organise for hand and foot prints and samples of hair to be taken for the parents if desired.

If parents/guardians feel strongly that they do not wish for a post-mortem examination to take place on their child, they can write a 'letter of objection' to the Coroner stating as much. Post-mortem examinations are now often waived unless the Coroner (or Forensic Pathologist) has a compelling reason to order one.

In most Coronial cases, the parents will be asked to wait to identify their child to the police as well as answer questions to assist the police prepare a report for the Coroner. Occasionally, where the child has been in the hospital for some time, identification of the child to the police can be performed by a member of staff.

### 9.3.5 Follow-up appointments for parents

Parents should be at least offered a follow-up appointment with the intensivist, social worker and co-consultants as appropriate in the weeks following the death. This provides an opportunity to clarify the events leading up to and surrounding their child's death, provide any further information that may have come to light since (for example, post-mortem results or cultures) as well as dispel any misunderstandings that the parents may have. Self-blame is common and reaffirmation of any decision to withholding/withdraw life-sustaining treatment is usually helpful.

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<sup>153</sup> J Sullivan, P Monagle & L Gillam, 'What parents want from doctors in end-of-life decision-making for children', *Archives of Disease in Childhood*, vol. 99, 2014, pp. 216–20, <http://www.ncbi.nlm.nih.gov/pubmed/24311188>.

## 9.4 Conclusion

The death of an infant or child is always a tragedy. However, as the intensivists caring for infants and children at the end of life, it is up to us as a team to ensure that we deliver not only the best medical care available, but also allow the parents/guardians to continue to feel close to their loved one and empowered to participate in the decision-making process to help determine what course truly represents the infant's or child's best interest.

The Institute of Medicine defined a decent or good death as:

*...one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.*<sup>154</sup>

Once it has become apparent that life-sustaining measures are no longer indicated, we must focus all our efforts on ensuring that we provide the child and their family with 'as good a death as possible' (see also Chapter 11 for a discussion of a 'good death').

**ANZICS recommendation:**

Intensivists should remember that the death of a child probably represents the worst moment of most parents' lives. Be generous with your time, be compassionate and kind, and be sincere.

**ANZICS recommendation:**

Some end-of-life decisions regarding children can be extremely difficult and involve some uncertainty. Intensivists are advised to consider discussing difficult cases with their colleagues, and to seek consensus between the team and family.

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<sup>154</sup> MJ Field & CK Cassel, *Approaching death: improving care at the end of life*, National Academies Press, Washington DC, 1997.

## Chapter 10 – Organ and tissue donation

Organ and tissue donation are an integral part of end-of-life care and should always be considered.

Most patients who die in ICU are able to donate tissue. All opportunities for organ donation should be recognised and preserved in circumstances where brain death is likely to occur, or where therapy is to be withdrawn and death is expected shortly afterwards.

Please see the *ANZICS Statement on Death and Organ Donation* for details of donation after brain death, donation after circulatory death and tissue-only donation.<sup>155</sup>

We recommend that the local donor agency should be contacted early, whenever organ or tissue donation is a possibility, for discussion and advice about suitability for donation, physiologic support of the potential donor, discussing donation with the family, determination of brain death, necessity for referral to the Coroner and documentation of cause of death (in non-coronial cases).

### **ANZICS recommendation:**

All opportunities for organ and tissue donation should be recognised and appropriately presented to the patient's family, in accord with the processes and recommendations in the *ANZICS Statement on Death and Organ Donation*.

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<sup>155</sup> The Australian and New Zealand Intensive Care Society, *The ANZICS Statement on Death and Organ Donation*, edn 3.2, 2013, <http://www.anzics.com.au/death-and-organ-donation>.

## Chapter 11 – Evaluating the quality of end-of-life care

### 11.1 Overview

This chapter presents information about:

- the importance of measuring the quality of end-of-life care
- principles of a good death
- suggestions for methods to evaluate end-of-life care.

Monitoring and evaluating practice can help to ensure best practice. Measurement of the quality of end-of-life care should be part of an ICUs audit processes, although there are some difficulties with this:

- The ultimate judge of the quality of end-of-life processes and the ICU is unable to participate in any feedback processes.
- A number of tools have been developed to measure the quality of end-of-life care (mostly from palliative care), they usually contain too many domains to be useful other than for research purposes.
- The delivery of a large questionnaire to families after the death of a loved one may be perceived as intrusive.

In most cases, whether the processes have met the expectations of the family or not will be obvious. Often, indicators of good performance include expressions of family gratitude at the time or afterwards and tangible expressions of gratitude such as donations and fundraising. Conversely, complaints either to the unit or external bodies obviously reflect processes with which the recipients are unhappy. In both of these circumstances, the attitude of families and their response is usually obvious at the time. The quality and clinical aspects of the process should be discussed at the unit Morbidity and Mortality Meeting.

### 11.2 Principles of a good death

The 12 principles of a good death are:<sup>156</sup>

1. To know when death is coming, and to understand what can be expected
2. To be able to retain control of what happens
3. To be afforded dignity and privacy
4. To have control over pain relief and other symptom control
5. To have choice and control over where death occurs
6. To have access to information and expertise of whatever kind is necessary

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<sup>156</sup> R Smith, 'A good death', *British Medical Journal*, vol. 320, 2000, pp. 129–30, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1128725/>.

7. To have access to a hospice care in any location, not only in hospital
8. To have access to any spiritual or emotional support required
9. To have control over who is present and who shares the end
10. To be able to issue Advance Care Directives that ensure wishes are respected
11. To have time to say goodbye, and control over other aspects of timing
12. To be able to leave when it is time to go, and not to have life prolonged indefinitely.

### 11.3 Evaluating the quality of end-of-life care

#### 11.3.1 Follow-up phone call

Not all of the 12 principles of a good death pertain to, or are possible, in the intensive care situation. One simple method of gaining some insight into the quality of the end-of-life care supplied in an ICU is to offer, at one of the final end-of-life conferences, the opportunity for the family to return if they have outstanding questions, wish to discuss post-mortem findings or if there are problems regarding billing.

A follow-up phone call is foreshadowed and at the time of that phone call, the three most relevant questions (see below) could be asked and the results tabled at the Morbidity and Mortality Meeting. The call is best performed by someone with a major involvement with the family and may be the doctor, nurse, social worker or chaplain.

After an initial enquiry as to how the family are managing and whether there is anything the caller can do to assist them, the three relevant questions to ask are:

1. Do you feel that the care offered was in keeping with the wishes of the patient?
2. Do you feel that the care offered to the patient and to the family, particularly with respect to communication and access to information, fulfilled the family's needs?
3. Do you have any suggestions as to how we might improve the care we offer to patients and families in these circumstances?

These questions summarise the major relevant items in the 12 principles as they pertain to intensive care and the answers provide useful discussion items to enable the staff as a group to assess their performance.

It is important that the information is fed back to the people involved in the care of the patient and discussed at appropriate internal meetings. Some evidence from New Zealand suggests that this process leads to improvement in the care provided.<sup>157</sup>

Trainees should be trained in end-of-life discussion by observing discussions then leading discussions under supervision before undertaking discussions on their own.

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<sup>157</sup> H Williams, S Cuthbertson, L Newby & SJ Streat, 'A follow-up service improves bereavement care in an intensive care unit', *Australian Critical Care*, vol. 12, 1999, p. 77.

SJ Cuthbertson, MA Margetts & SJ Streat, 'Bereavement follow-up service provided to the next-of-kin of patients who die following critical illness', *Critical Care Medicine*, vol. 28, 2000, pp. 1196–1201, <http://www.ncbi.nlm.nih.gov/pubmed/10809305>.

In addition, it may be useful to encourage experienced social workers and chaplains to always be present at family/doctor interactions so that the quality of performance and information can be assessed and early warning of problems can occur. This is particularly important when the discussion is proceeding badly and more senior help can be sought.

### 11.3.2 A case example of a bereavement follow-up service

#### **Case example**

A hospital critical care department provides a bereavement follow-up service to the next of kin of patients who die following critical illness. The procedures are described below.

#### **General practitioner contact**

On the first working day after death, the patient's GP is contacted by the clinical charge nurse and informed of the death.

#### **The bereavement follow-up service**

The critical care department provides a nurse-led bereavement follow-up service to the next of kin and the families/whanau of patients who have died following a critical illness.

The objectives of the bereavement follow-up service are to:

- determine how the next of kin are coping in early bereavement
- answer any unanswered questions
- ensure that the next of kin understand why their relative died
- facilitate resolution of issues by appropriate referral, information or family meeting.

Next of kin are informed of the bereavement follow-up service by an information sheet posted 7–14 days after the death.

Next of kin are contacted by telephone 4–8 weeks after the death and consent for interview is obtained. A structured telephone interview is undertaken on how the next of kin are coping, and about the experience they had during end-of-life care for their relative.

As appropriate, referrals are written, issues actioned and further family meetings arranged with intensivists if required.

The interview is entered into a database for analysis and continuous quality improvement initiatives.

### 11.3.3 Research and quality assurance of end-of-life care in ICU

If intensivists wish to do research or formally collect data for quality assurance, this reference<sup>158</sup> can be useful.

**ANZICS recommendation:**

Follow-up of **all** families whose members die in the ICU **and feedback to all ICU staff** is an important quality activity.

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<sup>158</sup> JE Nelson, JR Curtis, C Mulkerin et al., 'Choosing and using screening criteria for palliative care consultation in the ICU: a report from the Improving Palliative Care in the ICU (IPAL-ICU) Advisory Board', *Critical Care Medicine*, vol. 41, 2013, pp. 2318–2327, <http://www.ncbi.nlm.nih.gov/pubmed/23939349>.

## Appendices

### Appendix A – Contributors to the consultation process

Invitations to comment on the consultation draft of the Statement were forwarded to all ANZICS members, College of Intensive Care Medicine (CICM) members as well as relevant professional colleges and known interested parties. Fifty-eight submissions were received and considered in the review of the consultation draft.

The following organisations or representatives of the following organisations contributed:

Australian Medical Association (AMA)

Australian and New Zealand College of Anaesthetists (ANZCA)

Australian Commission on Safety and Quality in Health Care (ACSQHC)

New Zealand Nurses Organisation (NZNO)

Royal Australasian College of Physicians (RACP)

Royal Australasian College of Surgeons (RACS)

## Appendix B – Glossary

**Advance Care Directive:** a document that is completed by a person who has capacity, which records that person's preferences regarding future medical treatment. It may be a statutory defined document that is legally binding, or a common law document with which the doctor is also expected to comply.

**Advance Care Plan:** a written or verbal expression of preferences regarding future medical treatment, completed by a substitute decision-maker on behalf of a person who lacks capacity.

**AND ('allow a natural death'):** An alternative term to avoid the negative interpretation of withholding a potential therapy. If the term AND is used, it is important that it is a well-recognised term within that hospital and has clear documentation about what palliative care interventions should be initiated at the end of life (pain control/hydration/anxiolysis).

**Appropriate:** Appropriate medical treatment for a patient is considered a medical matter but the court can intervene (for more information see section 2.2.4). A decision reached through the consensus of all interested parties is more likely to be a well considered and appropriate decision and less likely to be subject to complaints or legal review.

**Authenticity:** Authenticity is the best understanding of what the patient's wishes would be in the current circumstances.

**Best interests:** The definition of the best interests is adapted from the Victorian legislation,<sup>159</sup> which states:

*In this Part, for the purposes of determining whether any special procedure or any medical or dental treatment would be in the best interests of the patient, the following matters must be taken into account—*

*(a) the wishes of the patient, so far as they can be ascertained; and*

*(b) the wishes of any nearest relative or any other family members of the patient; and*

*(c) the consequences to the patient if the treatment is not carried out; and*

*(d) any alternative treatment available; and*

*(e) the nature and degree of any significant risks associated with the treatment or any alternative treatment; and*

*(f) whether the treatment to be carried out is only to promote and maintain the health and well-being of the patient;...*

**Capacity:** Formal assessment of capacity is important in day-to-day clinical practice to assess a person's ability to participate in decision-making. It should be appreciated that capacity applies to the particular decision under consideration. Consequently, someone may be deemed to have impaired capacity for some decisions and still have capacity for other decisions where the concepts may be simpler.

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<sup>159</sup> Adapted from Victorian *Guardianship and Administration Act 1986* – Sect 38, [http://www.austlii.edu.au/au/legis/vic/consol\\_act/gaaa1986304/s38.html](http://www.austlii.edu.au/au/legis/vic/consol_act/gaaa1986304/s38.html).

For a person to have capacity to make a particular decision, clinicians should assess whether the patient:

- is able to understand the facts and the choices involved for that decision
- is able to weigh up the consequences
- has the capacity to communicate his or her decision.

Although some individuals or organisations may use the terms ‘competent’ and ‘non-competent’, this document uses the terms ‘capacity’ or ‘lack capacity’, except in Chapter 2 where the law refers to the term ‘competent’.

**Certainty:** see practical certainty.

**Consensus:** An opinion or decision reached by a group as a whole, where that decision can be supported by all members of the group even if it is not the most preferred opinion or position of each individual.

**DNR (‘do not resuscitate’):** Commonly used and clearly understood term when documenting end-of-life plans. It has been criticised for focusing on the withholding aspect of a therapy rather than the reality of not performing burdensome and ineffective treatments.

**End of life:** That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown. An ‘eventually fatal condition’ refers to a progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant illness and ageing. A person has an eventually fatal condition if their death in the foreseeable future would not be a surprise. The terms ‘eventually fatal’ or ‘terminal condition’ are used interchangeably.<sup>160</sup>

**End-of-life conflict:** Where disagreement has occurred as to the goals of care or treatment decisions at the end of life and where such conflict is not resolved by usual recourse to time and further discussion between the patient, their family and treating clinicians, as appropriate.

**Euthanasia:** The term euthanasia is ambiguous and should be avoided in ICU. However, as colleagues and families often mention it, an understanding of the term is important (see section 2.3.2). ANZICS recommends that intensivists completely refrain from using this term and simply describe exactly what actions are taking place (such as withdrawal of treatment) and not hint at either intent or result.

**Family:** For the purposes of this document the term family refers to those closest to the person in knowledge, care and affection. This includes the immediate biological family; the family of acquisition (related by marriage/contract); and the family of choice and friends (not related biologically or by marriage/contract).<sup>161</sup> It may include the Person Responsible, other relatives, partner (including same sex and de facto partners), or close friends according to any expressed

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<sup>160</sup> Palliative Care Australia, *Palliative and End of Life Care – Glossary of Terms*, 2008, <http://www.palliativecare.org.au/Portals/46/PCA%20glossary.pdf>.

<sup>161</sup> Canadian Palliative Care Association, *Standards for Palliative Care Provision*, June 1998.

wishes of the patient. This is distinct from the Person Responsible who has a formal substitute decision-making role on behalf of the patient under the NSW *Guardianship Act 1987*.<sup>162</sup>

**Futility:** Futility refers to the inability of a treatment to achieve the goals of care. As a concept, futility is subjective and probably not particularly helpful in discussions with families and patients. Honest and open discussions about poor outcomes should be held with the person and/or their family without using the term 'futile' (for more information see section 2.3.3.2).

**NFR ('not for resuscitation'):** Commonly used and clearly understood term when documenting end-of-life plans. It has been criticised for focusing on the withholding aspect of a therapy rather than the reality of not performing burdensome and ineffective treatments.

**Palliative care:** Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

World Health Organization's (WHO) Definition of Palliative Care for Children: Palliative care for children represents a special, albeit closely related field to adult palliative care. The WHO definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a).<sup>163</sup>

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

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<sup>162</sup> *Guardianship Act 1987* (NSW), [http://www.austlii.edu.au/au/legis/nsw/consol\\_act/ga1987136/](http://www.austlii.edu.au/au/legis/nsw/consol_act/ga1987136/).

<sup>163</sup> World Health Organization, *The WHO definition of palliative care*, <http://www.who.int/cancer/palliative/definition/en/>.

- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.<sup>164</sup>

**Practical certainty:** Practical certainty is the best understanding of the patient's prognosis and, in combination with authenticity, is a consideration in shared decision-making.

**Shared decision-making:** The process of shared decision-making involves a consensus among the patient (if the patient has the capacity to make decisions), a substitute decision-maker or family (if the patient does not have the capacity to decide), the intensive care team and other medical teams involved.

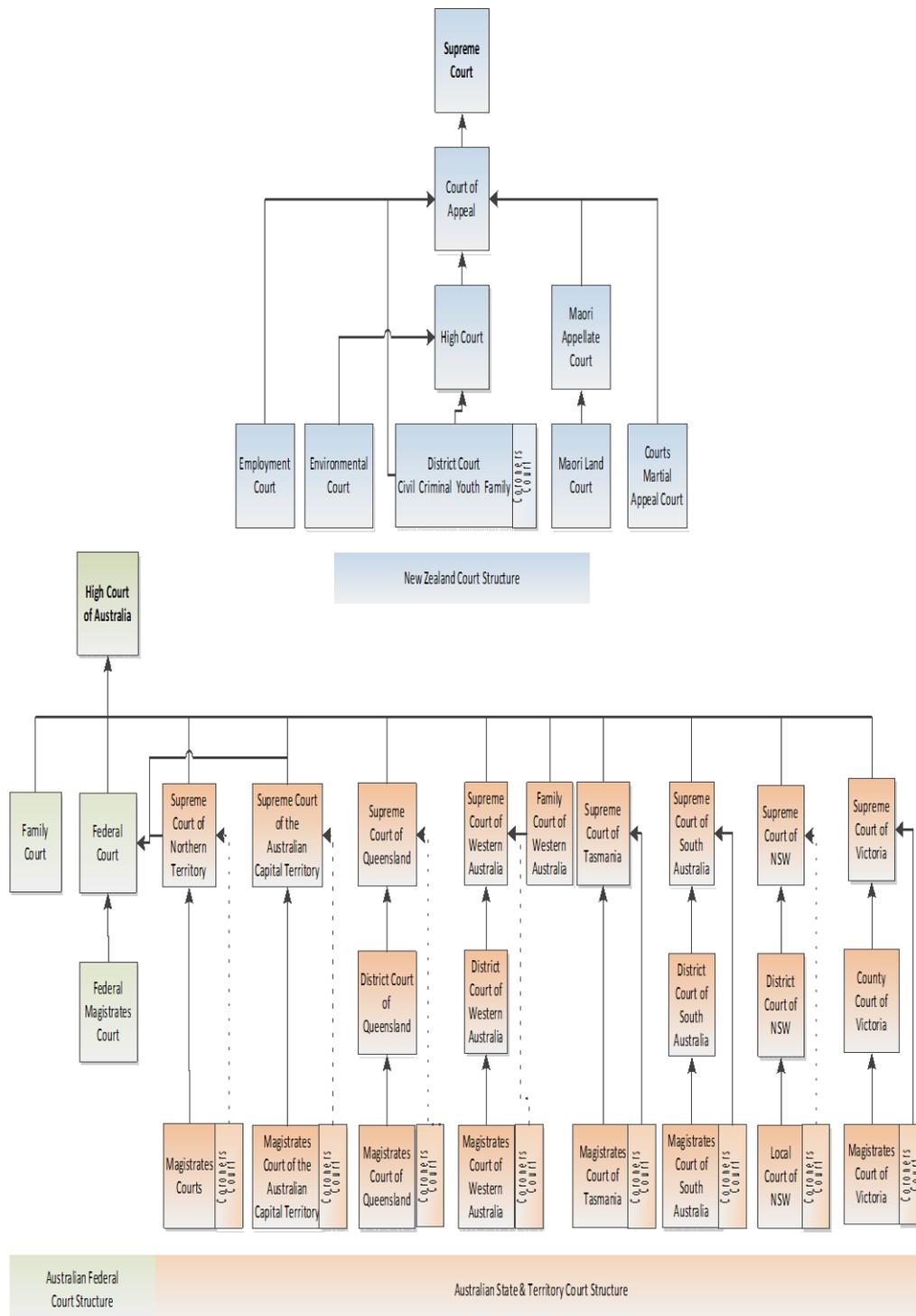
**Quality of life:** A very subjective term that is often used to discuss potential intensive care outcomes. It has a great deal of use when the communication comes from the family or patient in terms of levels of dependence and disability that they are willing to accept. There is a great deal of variability within the population as to what would be defined as an acceptable quality of life and thus clinicians should not impart their own perspectives in the discussion and should focus on more objective practical limitations – independence, toileting, feeding etc. Assessment of a quality of life has no place in assessments when conflict is present at the end of life (see section 2.3.3.1).

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<sup>164</sup> NSW Health, *Palliative Care Strategic Framework 2010–2013*, 2010 [reviewed 2014], [http://www0.health.nsw.gov.au/policies/pd/2010/PD2010\\_003.html](http://www0.health.nsw.gov.au/policies/pd/2010/PD2010_003.html).

## Appendix C – The Australian and New Zealand court hierarchies

More information about the courts of Australia and New Zealand is available.<sup>165</sup>



<sup>165</sup> Courts of New Zealand, <https://www.courtsofz.govt.nz/about/system/structure/diagram>. Australian Government, Department of Foreign Affairs and Trade, *About Australia. Legal system*, [https://www.dfat.gov.au/facts/legal\\_system.html](https://www.dfat.gov.au/facts/legal_system.html).

## Appendix D – The New Zealand legal system

### The New Zealand court system

The New Zealand court system comprises four levels: the District Court (and other specialty courts at the District Court Level such as the Coroners Court), the High Court, the Court of Appeal, and the Supreme Court. The High Court has both statutory jurisdiction and inherent common law jurisdiction and tends to hear the more serious jury trials, the more complex civil cases, administrative law cases and appeals from the decisions of courts and tribunals below it.

### The Consumers Code of Rights

In New Zealand, all health care services must be provided according to *The Health and Disability Commission Code of Health and Disability Services Consumers' Rights Regulations 1996*<sup>166</sup> (referred to hereafter as 'the Code'), which lists a number of rights of consumers and duties of providers including, among others, the right to be treated with respect (Right 1), the right to services of an appropriate standard (Right 4), the right to effective communication (Right 5), the right to be fully informed (Right 6), the right to make an informed choice and give informed consent (Right 7), the right to support (Right 8) and the right to complain (Right 10).

Under Right 7 (the right to make an informed choice and give informed consent) *The Code* states that:

*Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where -*

- a) It is in the best interests of the consumer; and*
- b) Reasonable steps have been taken to ascertain the views of the consumer; and*
- c) Either, -*
  - i. If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or*
  - ii. If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.*

Elsewhere in New Zealand law, the persons entitled to consent on behalf of the consumer are specified as:

- a parent or guardian of a minor
- a person holding enduring power of attorney for health care
- a court-appointed welfare guardian.

However, these persons cannot refuse standard treatment intended to save life or prevent serious damage to health.

Under New Zealand law there is no general doctrine of legal consent from relatives to treatment on behalf of an adult who lacks capacity.

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<sup>166</sup> Health and Disability Commissioner, *Code of Health and Disability Services Consumers' Rights Regulations 1996*, <http://www.hdc.org.nz/the-act--code/the-code-of-rights>.

There is no breach of the Code if the provider has taken reasonable actions in the circumstances to give effect to the rights and comply with the duties specified. ‘The circumstances’ are defined as all the relevant circumstances, including the consumer’s clinical circumstances and the provider’s resource constraints.

Complaints under the Code are dealt with by the Health and Disability Commission. A breach of the Code is not illegal but can (and does) lead to professional disciplinary action. The Health and Disability Commission has not yet had occasion to make any decisions relating to withdrawal or withholding treatment.

### **New Zealand law relevant to end-of-life care in the ICU**

New Zealand law relevant to end-of-life care in the ICU comprises:

1. *Crimes Act 1961*<sup>167</sup>
2. *New Zealand Bill of Rights Act 1990*<sup>168</sup>
3. Relevant case law.

Although Māori cultural needs have been incorporated into various legislation, there is no separate legislative provision for end-of-life care for Māori.

#### ***Crimes Act 1961***

The Crimes Act states that every one:

- ‘who has charge of any other person... is under a legal duty to supply that person with the necessaries of life, and is criminally responsible for omitting without lawful excuse to perform such duty if the death of that person is caused... by such omission’ (Section 151. Duty to provide the necessaries of life), and
- ‘who by any act or omission causes the death of another person kills that person although the effect of the bodily injury... was merely to hasten his death while labouring under some disorder or disease arising from some other cause’ (Section 164. Acceleration of death).’

#### ***New Zealand Bill of Rights Act 1990***

The *New Zealand Bill of Rights Act 1990* states that:

- ‘no one shall be deprived of life except on such grounds as are established by law and are consistent with the principles of fundamental justice’ (Right 8. Right not to be deprived of life), and
- ‘everyone has the right to refuse to undergo any medical treatment’ (Right 11. Right to refuse to undergo any medical treatment).’

#### **Relevant case law**

In New Zealand, it is extremely rare for clinicians or patients to resort to the courts to make a judgement on issues around medical treatment and there have been only three cases relevant to end-of-life care:

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<sup>167</sup> *Crimes Act 1961* (New Zealand), <http://www.legislation.govt.nz/act/public/1961/0043/latest/whole.html#DLM327394>.

<sup>168</sup> *New Zealand Bill of Rights Act 1990*, <http://www.legislation.govt.nz/act/public/1990/0109/latest/DLM224792.html>.

**Case 1:** *Re L. Auckland Area Health Board v Attorney General* (1993) 1 NZLR 235<sup>169</sup>

Mr L was a 59-year-old man with severe acute ascending polyneuropathy who became completely denervated in all somatic and examinable cranial nerves, although he retained EEG activity and visual evoked potentials. He was ventilated in ICU for over a year without any signs of recovery.

The medical staff and family agreed to withdrawal of therapy but some of the nursing staff at that time were concerned that withdrawal of the ventilation would amount to killing him.

The doctors sought a declaratory judgement from the High Court that removal from the ventilator would not be culpable homicide under the *Crimes Act 1961*.<sup>170</sup>

The judge ruled that ventilation of a patient beyond recovery was not a 'necessary of life' and that withdrawal of ventilation serving no therapeutic or medical benefit in accordance with recognised medical opinion was 'lawful excuse' and would not legally 'cause' death.

On the evening that the judgement was made, the ventilator was withdrawn and Mr L died.

**Case 2:** The Rau Williams case. *Shortland v Northland Health Limited* (1998) 1 NZLR 433<sup>171</sup>

This case concerned a 63-year-old diabetic man with chronic renal failure and dementia who had nobody to care for him at home. He was admitted to hospital and given temporary peritoneal dialysis while he was assessed for suitability for the haemodialysis program. The clinicians judged that he was not suitable for haemodialysis and discontinued peritoneal dialysis after two months.

The family sought a judicial order to continue dialysis and the case went to the Court of Appeal. The judgement was that to require consent to cease treatment (or not to give treatment) gives the family power to require treatment, and that the law cannot countenance such a proposition.

Accordingly, Mr Williams was not given further peritoneal dialysis and he died.

**Case 3:** The case of Baby L. *Auckland Healthcare Services Ltd v L & L* [1998] NZLR 17 FRNZ 376, (1998) NZFLR 998 (HC).<sup>172</sup>

This case concerned a two-month-old baby in intensive care with severe brain stem and lung maldevelopment, who was ventilator dependent and expected to die within weeks or months in spite of treatment.

The parents would not agree to withdrawal of therapy and the hospital petitioned the High Court for court-ordered guardianship.

The court considered that in all but exceptional cases the court is required to take steps to preserve human life but that a decision not to give or maintain life-prolonging treatment may be taken in the best interests of the patient and having regard to established medical practice.

The court's decision was that withdrawal of support in the best interests of the patient was not a breach of the right not to be deprived of life, and that the wishes of the parents, while of the greatest significance, cannot always be the determining factor.

Accordingly, ventilation was withdrawn and Baby L died.

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<sup>169</sup> *L, Re Auckland Area Health Board v Attorney-General* (1993) 1 NZLR 235 9.

<sup>170</sup> *Crimes Act 1961* (New Zealand), <http://www.legislation.govt.nz/act/public/1961/0043/latest/whole.html#DLM327394>.

<sup>171</sup> *Shortland v Northland Health Limited* (1998) 1 NZLR 433.

<sup>172</sup> *Auckland Healthcare Services Ltd v L & L* [1998] NZLR 17 FRNZ 376, (1998) NZFLR 998 (HC).

## Appendix E – Advance care planning documents

### Advance Care Directive – for person with legal capacity (example)

**Advance Care Directive**  
**A record of my future health care wishes**

I, \_\_\_\_\_ of \_\_\_\_\_  
 declare that:

- 1) My current health problems include: \_\_\_\_\_
- 2) This document has been explained to me and I understand its importance and purpose. I may complete all or part of this document. It is a guide for my future medical treatment. It will only be used if I am unable to make decisions for myself, and will be taken into account when determining my treatment.
- 3) I understand that it is important to discuss my wishes with my doctor, and my family, including the Substitute Decision-Maker (if appointed).
- 4) I request that my wishes, and the beliefs and values on which they are based, are respected. I have written on page 2 of this form the things that I value most in life, and other things that may help my doctors and other decision makers.
- 5) I understand that doctors will only provide treatment that might be medically beneficial. I also understand that irrespective of any decisions by the doctor about CPR and life prolonging treatment, I will continue to be cared for, including care to relieve pain and alleviate any suffering.

**A**

**CPR (Cardiopulmonary Resuscitation) *Initial appropriate box***

It has been explained to me by Dr \_\_\_\_\_ that I would not benefit from attempted CPR and I understand and accept this.

**OR**

**I would like** CPR attempted if it might be medically beneficial.

**OR**

**I do NOT want CPR**, even if the doctors think it could be beneficial.

**AND**

**Life Prolonging Treatments *Initial appropriate box***  
 e.g. breathing machine (ventilator), kidney machine (dialysis), feeding tube, surgery

**I would like** life prolonging treatment in order to prolong my life as long as possible.

**OR**

**I would like** life prolonging treatments only if the doctors expect a reasonable outcome. To me, a reasonable out come means: \_\_\_\_\_

**OR**

**I do NOT** want life prolonging treatments at all. If life prolonging treatment has been commenced I request that it be discontinued and that I receive palliative care.

**OR**

**C**

I choose to delegate decisions regarding CPR and life prolonging treatments to my Substitute Decision-Maker (SDM) or the following person:

\_\_\_\_\_

(insert name of SDM and contact number)

OR \_\_\_\_\_

(insert name and relationship)

The things that I most value in my life are: (eg. independence, enjoyable activities, talking to family and friends):

\_\_\_\_\_

\_\_\_\_\_

Future situations that I would find unacceptable in relation to my health:

\_\_\_\_\_

\_\_\_\_\_

Specific treatments that I would NOT want considered for me :

\_\_\_\_\_

\_\_\_\_\_

Other things that I would like known, which may help with making decisions about my future medical treatment:

\_\_\_\_\_

\_\_\_\_\_

I ask that, if possible, my Substitute Decision-Maker and/or family include the following people in discussions and decisions about my health care: \_\_\_\_\_

\_\_\_\_\_

If I am nearing death I would like the following: (for example, music, spiritual care, customs or cultural beliefs met, family members present):

\_\_\_\_\_

This is a true record of my wishes on this date.	
My Signature _____	Date _____
Witness' signature _____ <i>(preferably Substitute Decision-Maker)</i>	Witness name (Print) _____
I, Dr _____ (Registered Medical Practitioner)	believe that _____ <i>(your name)</i>
is competent and understands the importance and implications of this document.	
<b>Doctor's signature</b> _____	Date _____

**The contents of this Advance Care Directive have also been discussed with:**

Name: _____	Name: _____
Relationship: _____	Relationship: _____
Signature: _____	Signature: _____
Date: _____	Date: _____

**Advance Care Plan – for person without legal capacity – to be completed by the substitute decision-maker (example)**

<p><b>Advance Care Plan</b>          For a non-competent person  <b>A record of future health care wishes</b></p>	<p>Health Service LOGO</p>
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This document relates to the following person: \_\_\_\_\_  
 of \_\_\_\_\_  
 (person's address)

- 1) I understand that he/she has been assessed as not having legal capacity to appoint a Substitute Decision-Maker or make medical decisions independently.
- 2) This person has the current health problems\*: \_\_\_\_\_
- 3) This document has been explained to me and I understand its importance and purpose. I may complete all or part of this document. It is a guide and will be taken into account when determining future medical treatment for this person.
- 4) I request that this person's wishes, beliefs and values on which these decisions are based, are respected. I have written on this form the things that they value most in life, and other things that may help their doctors and other decision makers.
- 5) I understand that doctors will only provide treatment that might be medically beneficial. I also understand that, irrespective of any decisions by the doctor about CPR and life prolonging treatment, he/she will continue to be cared for, including care to relieve pain and alleviate any suffering.

**A**

**CPR (Cardiopulmonary Resuscitation) Initial appropriate box**

It has been explained to me by Dr \_\_\_\_\_ that he/she would not benefit from attempted CPR and I understand and accept this.

**OR**

I would like CPR attempted on him/her if it might be medically beneficial.

**OR**

I do NOT want CPR for him/her even if the doctors think it could be beneficial.

**AND**

**B**

**Life Prolonging Treatments Initial appropriate box**  
 e.g. breathing machine (ventilator), kidney machine (dialysis), feeding tube, surgery

I would like life prolonging treatment for him/her in order to prolong their life as long as possible

**OR**

I would like life prolonging treatments for him/her only if the doctors expect a reasonable outcome. By reasonable outcome I mean: \_\_\_\_\_

**OR**

I do NOT want life prolonging treatments for him/her at all. If life prolonging treatment has been commenced on him/her I request that it be discontinued and that he/she receive palliative care.

\* If you are the Substitute Decision-Maker, refer to Information Sheet.

The things that he/she most values are: (eg. independence, enjoyable activities, family and friends):

\_\_\_\_\_

\_\_\_\_\_

Future state(s) of health that he/she would find unacceptable:

\_\_\_\_\_

\_\_\_\_\_

Specific treatments I believe he/she would NOT want:

\_\_\_\_\_

\_\_\_\_\_

Other things I would like known about him/her which may help with future medical decisions:

\_\_\_\_\_

\_\_\_\_\_

If he/she is nearing death I would like the following (for example, music, spiritual care, customs or cultural beliefs met, family members present):

\_\_\_\_\_

\_\_\_\_\_

<p>I have hereby made choices based on the best interests of _____  <small>(insert non competent persons name), taking into account their wishes, the wishes of family members and significant others, and the benefits and burdens of treatment. I request that the stated choices recorded are respected by health professionals, now and in the future.</small></p>	
<p>Name _____</p>	
<p>Signature _____</p>	<p>Date _____</p>
<p>Relationship to person _____ Substitue Decision-Maker</p>	
<p>I, Dr _____ believe that _____  <small>(Registered Medical Practitioner) (Substitue Decision-Maker)</small></p>	
<p>is acting in the best interests of and on behalf of the person stated above. The Substitue Decision-Maker understands the importance and implications of this document.</p>	
<p><b>Doctor's signature</b> _____</p>	<p>Date _____</p>

**The contents of this Advance Care Plan have also been discussed with:**

Name: _____	Name: _____
Relationship: _____	Relationship: _____
Signature: _____	Signature: _____
Date: _____	Date: _____

=May 2009

**Resuscitation Plan – to be completed by the doctor (example)**

Health Service Logo	Surname ..... Given Name(s) ..... Date of Birth ..... <p style="text-align: center;"><b>AFFIX PATIENT LABEL HERE</b></p>
<b>Complete <u>either</u> section A or section B <u>AND</u> complete the Reason for Decision in section C.</b>	
<div style="border: 1px solid black; padding: 5px;"> <p><b>A Patient is for treatment aimed at PROLONGING LIFE</b> (Tick one option only) <span style="float: right;"><u>Guide to staff</u></span></p> <p><input type="checkbox"/> Patient is for FULL TREATMENT including CPR <span style="float: right;">▶ For Code Blue</span></p> <p style="text-align: center;"><b>OR</b></p> <p><input type="checkbox"/> Patient is NOT FOR CPR (but is for intubation for respiratory failure) <span style="float: right;">▶ For Code Blue</span></p> <p style="text-align: center;"><b>OR</b></p> <p><input type="checkbox"/> Patient is NOT FOR CPR OR INTUBATION (but is for non-invasive ventilation or inotropes) <span style="float: right;">▶ Not for Code Blue For MET call</span></p> <p style="text-align: center;"><b>OR</b></p> <p><input type="checkbox"/> Patient is NOT FOR CPR, INTUBATION, OR VENTILATION but is for the following ACTIVE MANAGEMENT: (eg. antibiotics, tube feeding) <span style="float: right;">▶ Not for Code Blue For MET call</span></p> <p>Must specify: _____ <span style="float: right;"><input type="checkbox"/> Yes <input type="checkbox"/> No</span></p> <p>_____</p> <p style="font-size: small;">(CPR = Cardio-Pulmonary Resuscitation- provision of cardiac compression, ventilation, DC reversion)</p> </div> <p style="text-align: center; margin: 5px 0;"><b>OR</b></p> <div style="border: 1px solid black; padding: 5px;"> <p><b>B Patient is for treatment aimed at SYMPTOM MANAGEMENT</b> <span style="float: right;">▶ Not for Code Blue or MET call</span></p> <p>Ensure that palliative care plan has been made, and medication prescribed</p> <p>Indicate other medical orders (consider appropriateness of other treatments, investigations, review all medications)</p> <p>_____</p> </div>	
<div style="border: 1px solid black; padding: 5px;"> <p><b>C REASON FOR DECISION: (tick all that apply)</b></p> <p><input type="checkbox"/> Medical decision based on what is medically indicated for this patient. Reason for decision: _____</p> <p>Has patient been informed of decision?    <input type="checkbox"/> YES    <input type="checkbox"/> NO    <input type="checkbox"/> previously informed    <input type="checkbox"/> N/A</p> <p>Has family been informed of this decision?    <input type="checkbox"/> YES    <input type="checkbox"/> NO    <input type="checkbox"/> previously informed    <input type="checkbox"/> N/A</p> <p><input type="checkbox"/> Decision of competent patient or Substitute Decision-Maker (SDM)</p> <p><input type="checkbox"/> Family has indicated that additional treatment is not in the patient's best interests and the doctor concurs</p> <p>Name of Substitute Decision-Maker: _____ Relationship to patient: _____</p> </div>	

Resuscitation Plan Medical Records Code

Doctor's signature: \_\_\_\_\_ Doctor's Name: \_\_\_\_\_

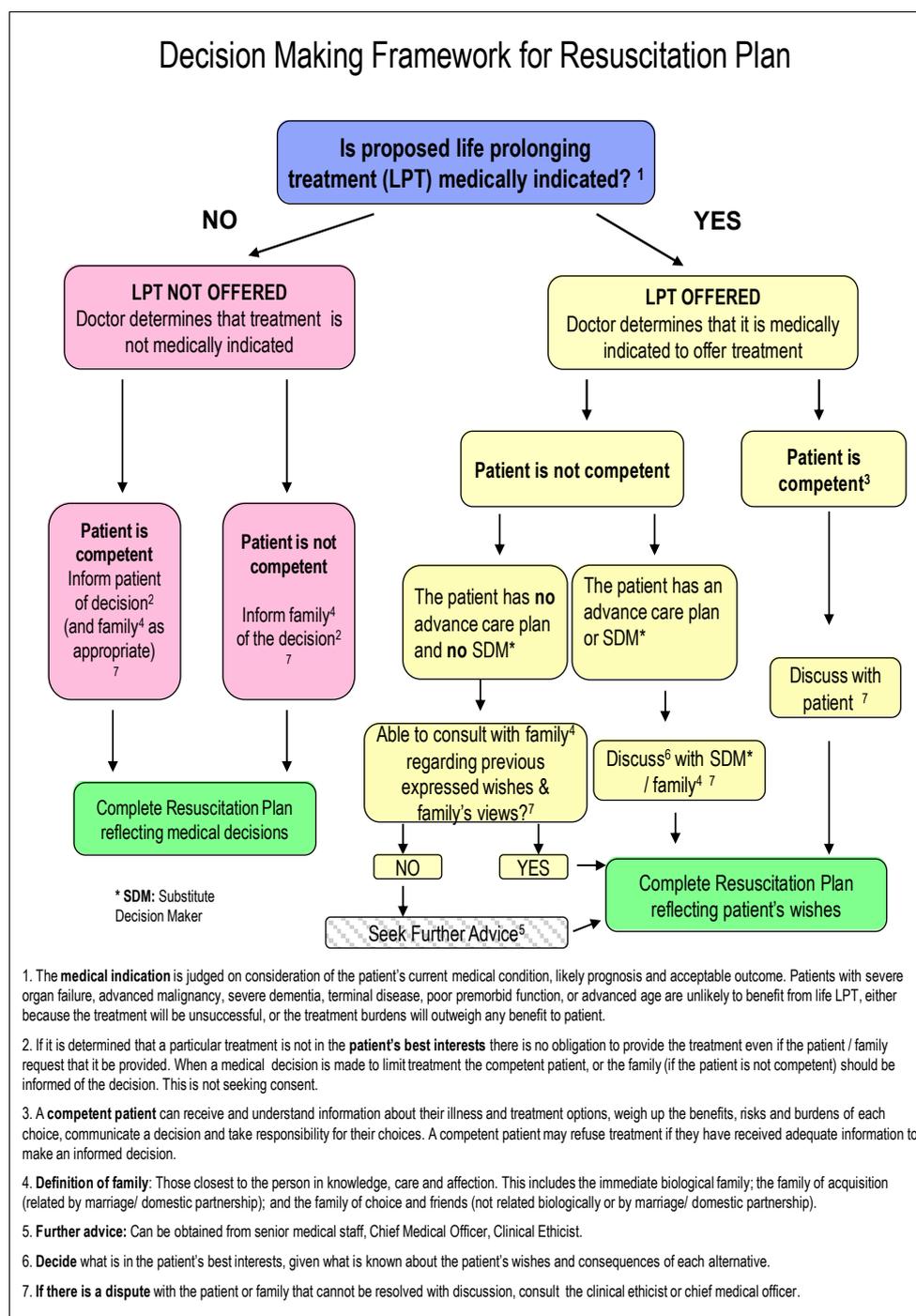
Doctor's Position: \_\_\_\_\_ Date: \_\_\_\_\_

Consultant who approved: \_\_\_\_\_

**If changes are required the Plan should be rewritten and the old Plan crossed through and marked "VOID"**

=

## Guidance for doctor on reverse page of resuscitation plan



## Appendix F – ICU Palliative Care Plan (example)

### ICU Palliative Care Plan

#### During Limitation and/or Withdrawal of Treatment in ICU

When a medical decision has been made to limit or withdraw therapy, the emphasis of care should be on patient comfort. This document sets out the medical orders and guides nursing management.

<b>MEDICAL ORDER SHEET</b>		Consultant: _____	Nursing signature	Medical signature
Completed by: _____		Signature: _____		
Medical treatment consensus established: Date: _____		Time: _____		
<b>Patient &amp; Family:</b>				
Patient's wishes determined <i>Discussion with patient and/or family and/or review of advance care directive</i>				
Family/NOK assent to limitation/withdrawal of treatment				
Patient's/family's wishes regarding organ & tissue donation identified				
Family Meeting documented in medical records				
<b>Resuscitation status:</b>				
Resuscitation Plan completed				
<b>Comfort measures for Pain, Anxiety &amp; Dyspnoea:</b>				
Drugs prescribed to relieve pain, anxiety or dyspnoea <i>(Prescription should include dose {range for infusions}, route of administration &amp; target effect e.g. Morphine 1-10mg/h plus 5mg IV boluses pm, for pain)</i>				
<b>Respiratory Management (Intubated patients):</b>		<b>Time</b>		
Change mode to PSV				
Reduce FiO <sub>2</sub> : to room air <b>OR</b> to _____ % (Circle)				
Extubate				
Other:				
<b>Inotropes:</b> Drug:		<b>Time</b>		
Cease <input type="checkbox"/> <b>OR</b> Do not increase dose > _____				
Other:				
<b>Other Therapies/Monitoring to be discontinued:</b>				
IV fluids	<input type="checkbox"/>	ABGs	<input type="checkbox"/>	
Enteral feeding/TPN	<input type="checkbox"/>	Daily blood tests	<input type="checkbox"/>	
CRRT (Haemofiltration)	<input type="checkbox"/>	X-rays	<input type="checkbox"/>	
Medications ( <i>cease on drug chart</i> )	<input type="checkbox"/>	Bedside monitoring*	<input type="checkbox"/>	
Frequency of documented obs	/24	Other _____	<input type="checkbox"/>	

\* Continue to use the central monitor to follow the patient's progress.

## Appendix G – Summary of useful government websites

Website name	Organisation	Target Audience(s)	Topics	Consumer focus	Comments
New Zealand Legislation <a href="http://www.legislation.govt.nz/">http://www.legislation.govt.nz/</a>	New Zealand Parliamentary Counsel Office/Te Tari Tohutohu Pāremata, New Zealand Government	Community	Authoritative source of Acts, Bills and Legislative Instruments		The website provides official legislation in PDF format
Australian Guardianship and Administrative Council <a href="http://www.agac.org.au/">http://www.agac.org.au/</a>	Has links to all State bodies for guardianship tribunals, public guardians and public trustees				
<b>NEW SOUTH WALES</b>					
Planning ahead tools <a href="http://www.planningaheadtools.com.au">http://www.planningaheadtools.com.au</a>	Developed by NSW Office for Ageing, NSW Trustee and Guardian and NSW Public Guardian  Developed for NSW Planning Ahead for Later Life forum	Community  Health professionals  Legal professionals	Wills POA EG Capacity	Yes	Able to create own menu  Able to create own plan, which is saved and printed  Short videos  Links to existing videos and resources
NSW Civil and Administrative Tribunal (NCAT) <a href="http://www.ncat.nsw.gov.au/">http://www.ncat.nsw.gov.au/</a>	Guardianship Division of NCAT	Community	EG POA		Links to planning ahead tools

Website name	Organisation	Target Audience(s)	Topics	Consumer focus	Comments
NSW Public Guardian <a href="http://www.publicguardian.lawlink.nsw.gov.au/publicguardian/pg_index.html">http://www.publicguardian.lawlink.nsw.gov.au/publicguardian/pg_index.html</a>	NSW Public Guardian	Community	EG POA		Links to planning ahead tools
NSW Health – advance care planning <a href="http://www.health.nsw.gov.au/patients/acp/pages/default.aspx">http://www.health.nsw.gov.au/patients/acp/pages/default.aspx</a>		Community			Good FAQs and links
Agency for Clinical Innovation (ACI) <a href="http://www.aci.health.nsw.gov.au/">http://www.aci.health.nsw.gov.au/</a>		Professionals			Big range of documents on ACP
<b>WESTERN AUSTRALIA</b>					
Advance Health Directives (AHD) <a href="http://www.health.wa.gov.au/advancehealthdirective/home/">http://www.health.wa.gov.au/advancehealthdirective/home/</a>	Department of Health		Update on legislative changes	No translations obvious	Useful resources for community and staff  Includes simple online course for staff
Office of the Public Advocate (Enduring Power of Attorney) <a href="http://www.publicadvocate.wa.gov.au/E/enduring_power_of_attorney.aspx?uid=4607-1285-4846-1893">http://www.publicadvocate.wa.gov.au/E/enduring_power_of_attorney.aspx?uid=4607-1285-4846-1893</a>	Department of the Attorney General		POA (enduring power of attorney, EPA)	No translations obvious	<i>Guardianship and Administration Act 1990</i>
Office of the Public Advocate (Enduring Power of Guardianship) <a href="http://www.publicadvocate.wa.gov.au/E/enduring_power_of_guardianship.aspx?uid=3339-2085-8696-8396">http://www.publicadvocate.wa.gov.au/E/enduring_power_of_guardianship.aspx?uid=3339-2085-8696-8396</a>	Department of the Attorney General		EG	No translations obvious	

Website name	Organisation	Target Audience(s)	Topics	Consumer focus	Comments
<b>SOUTH AUSTRALIA</b>					
Advance Care Directive and anticipatory directions <a href="http://www.advancecaredirectives.sa.gov.au/">http://www.advancecaredirectives.sa.gov.au/</a>	SA Health			No translations obvious	Has information and resources about Advance Care Directive and anticipatory directions
Government portal for seniors for POA and AD <a href="http://www.sa.gov.au/topics/seniors/legal-issues/power-of-attorney-and-advance-directives">http://www.sa.gov.au/topics/seniors/legal-issues/power-of-attorney-and-advance-directives</a>	Government of South Australia	Community – seniors	POA Enduring POA Advance Care Directives		Simple one page introduction with links to more specific sites
Guardianship Board <a href="http://www.guardianshipboard.sa.gov.au/homepage">http://www.guardianshipboard.sa.gov.au/homepage</a>	Government of South Australia		Administration orders Guardianship orders		
South Australian Public Advocate <a href="http://www.opa.sa.gov.au/what_we_do">http://www.opa.sa.gov.au/what we do</a>	Similar to Public Guardian in NSW		Enduring power of guardianship EPOA MPOA Anticipatory direction	No translations	General information and a good presentation by the Director

Website name	Organisation	Target Audience(s)	Topics	Consumer focus	Comments
Public Trustee <a href="http://www.publictrustee.sa.gov.au/">http://www.publictrustee.sa.gov.au/</a>			Wills  EPOA	Yes	
<b>NORTHERN TERRITORY</b>					
Adult Guardianship <a href="http://health.nt.gov.au/Aged_and_Disability/Adult_Guardianship/index.aspx">http://health.nt.gov.au/Aged_and_Disability/Adult_Guardianship/index.aspx</a>					Very brief description of adult guardianship and contact details
Power of Attorney <a href="http://www.nt.gov.au/justice/bdm/land_title_office/power.shtml#">http://www.nt.gov.au/justice/bdm/land_title_office/power.shtml#</a>	Department of the Attorney-General and Justice		Information about POA  Does not seem to have any brochure that can be printed		
The Office of the Public Guardian <a href="http://www.hss.gov.nt.ca/social-services/office-public-guardian">http://www.hss.gov.nt.ca/social-services/office-public-guardian</a>	Government of Northwest Territories, Department of Health and Social Services		Guardianship		
Office of Public Trustee <a href="http://www.nt.gov.au/justice/pubtrust/">http://www.nt.gov.au/justice/pubtrust/</a>	Department of the Attorney-General and Justice				
Department of Health – Palliative care <a href="http://www.health.nt.gov.au/Palliative_Care/">http://www.health.nt.gov.au/Palliative_Care/</a>	Northern Territory Government				
<b>TASMANIA</b>					
Guardianship and Administration Board <a href="http://www.guardianship.tas.gov.au/about_us">http://www.guardianship.tas.gov.au/about_us</a>	Tasmanian Government		Guardianship, EG, EPOA, Wills	No translations obvious	

Website name	Organisation	Target Audience(s)	Topics	Consumer focus	Comments
Office of the Public Guardian – Enduring Guardianship <a href="http://www.publicguardian.tas.gov.au/enduring_guardianship">http://www.publicguardian.tas.gov.au/enduring_guardianship</a>	Tasmanian Government		Links to more information about EG	No translations obvious	
Office of the Public Guardian – Enduring Power of Attorney <a href="http://www.publicguardian.tas.gov.au/enduring_powers_of_attorney">http://www.publicguardian.tas.gov.au/enduring_powers_of_attorney</a>	Tasmanian Government		No further information or forms here	No translations obvious	
Public Trustee <a href="http://publictrustee.tas.gov.au/">http://publictrustee.tas.gov.au/</a>			Wills  EPOA  Financial administration	No translations obvious	
Department of Health and Human Services – Palliative Care <a href="http://www.dhhs.tas.gov.au/palliativecare/advance_care_planning_for_healthy_dying">http://www.dhhs.tas.gov.au/palliativecare/advance_care_planning_for_healthy_dying</a>	Tasmanian Government		Advance care planning		Links to information about ‘capacity toolkit’ further information about ACDs, ACD forms and more
<b>VICTORIA</b>					
Office of the Public Advocate <a href="http://www.publicadvocate.vic.gov.au/">http://www.publicadvocate.vic.gov.au/</a>	Victorian Department of Justice		POA  Administration and guardianship  Medical consent		Has a good booklet, ‘Take Control’  Range of brochures in 12 languages

Website name	Organisation	Target Audience(s)	Topics	Consumer focus	Comments
Guardianship and Administration section of the Victorian Civil and Administrative Tribunal (VCAT) <a href="http://www.vcat.vic.gov.au/disputes/guardians-administrators/Array/guardianship-and-administration-act-1986-applications">http://www.vcat.vic.gov.au/disputes/guardians-administrators/Array/guardianship-and-administration-act-1986-applications</a>			Guardianship Administrators  Enduring POA (financial)  Enduring POA (medical treatment)		Guardianship tribunal function only – not much information on anything else
Victorian Health Department – Advance care planning <a href="http://www.health.vic.gov.au/acp/">http://www.health.vic.gov.au/acp/</a>					Has videos and links to more information  Link to: <i>The Advance care planning: have the conversation. A strategy for Victorian health services 2014–2018</i>

AUSTRALIAN CAPITAL TERRITORY					
ACT Civil and Administrative Tribunal (ACAT) <a href="http://www.acat.act.gov.au/">http://www.acat.act.gov.au/</a>			This Tribunal seems to cater for all sorts of disputes including guardianship and management of property		Website not very user-friendly
Public Advocate of the ACT <a href="http://www.publicadvocate.act.gov.au/">http://www.publicadvocate.act.gov.au/</a>	ACT Government		Guardianship  EPOA		
Public Trustee ACT (PTACT) <a href="http://www.publictrustee.act.gov.au/">http://www.publictrustee.act.gov.au/</a>	ACT Territory Authority		Wills  Trusts  POA		
ACT Health – Respecting patient choices <a href="http://www.health.act.gov.au/consumer-information/respecting-patient-choices">http://www.health.act.gov.au/consumer-information/respecting-patient-choices</a>	ACT Health		Minimal information about ACP, respecting patient choices		Links to Advance Care Planning Australia <a href="http://advancecareplanning.org.au/">http://advancecareplanning.org.au/</a>

QUEENSLAND					
Guardianship <a href="http://www.justice.qld.gov.au/justice-services/guardianship">http://www.justice.qld.gov.au/justice-services/guardianship</a>	Queensland Government		Good range of information and forms for: POA Guardianship ACD	Some translated factsheets	Links to good sections on: Adult guardians POA Planning for life
Office of the Public Advocate <a href="http://www.justice.qld.gov.au/justice-services/guardianship/public-advocate">http://www.justice.qld.gov.au/justice-services/guardianship/public-advocate</a>	Queensland Government		Guardianship		
Public Trustee <a href="http://www.pt.qld.gov.au/">http://www.pt.qld.gov.au/</a>	Queensland Government				Much like trustees in other states
Advance care planning online <a href="http://apps.health.qld.gov.au/acp/HOME.aspx">http://apps.health.qld.gov.au/acp/HOME.aspx</a>	Queensland Health			Yes	Excellent resource that takes people through the process of ACP and has the contents available as a downloadable booklet Also has online program for staff

ACD = Advance Care Directives

ACP = Advance care planning

EG = Enduring Guardianship

EPOA = Enduring Power of Attorney

MPOA = Medical Power of Attorney

POA = Power of Attorney