Implementation Guidelines

End-of-life care: Decision-making for withholding and withdrawing life-sustaining measures from adult patients

Part 1

Legal Framework and Clinical Considerations

Ethics Team
Clinical Policy Unit
Centre for Healthcare Improvement
email: QHclinicalethics@health.qld.gov.au
Table of Contents

EXECUTIVE SUMMARY ............................................................................................................. 4
POLICY STATEMENT .................................................................................................................. 5
QUEENSLAND HEALTH PRINCIPLES FOR DECISION-MAKING ABOUT LIFE-SUSTAINING MEASURES .................................................................................................................. 5
SUMMARY OF KEY POINTS IN THE FOUR GOVERNING PRINCIPLES .................................. 6
1.0 INTRODUCTION .................................................................................................................... 7
2.0 LEGISLATIVE FRAMEWORK ............................................................................................... 8
  2.1 Queensland Legislation ....................................................................................................... 8
  2.2 Life-sustaining measures ................................................................................................. 9
  2.3 Good medical practice .................................................................................................... 10
  2.4 Capacity .......................................................................................................................... 11
    2.4.1 Competency and capacity ......................................................................................... 12
    2.4.2 Assessing capacity ................................................................................................... 12
    2.4.3 Patients with borderline or fluctuating capacity ....................................................... 13
  2.5 Emergency situations ...................................................................................................... 13
    2.5.1 Acute emergencies .................................................................................................. 14
    Providing life-sustaining measures in acute emergency situations ..................................... 14
    Withholding or withdrawing life-sustaining measures in acute emergency situations ........ 14
    2.5.2 Non-acute situations ............................................................................................... 16
  2.6 Transparency and accountability .................................................................................... 16
    2.6.1 Documentation/process audit post-death ................................................................ 17
    2.6.2 Acute Resuscitation Plans (ARP) ........................................................................... 17
    2.6.3 Reviewing ARPs and Advance Health Directives ................................................... 18
    2.6.4 Protections for health professionals ...................................................................... 18
Legislative Framework - Summary Points .............................................................................. 19
3.0 CONSENT ............................................................................................................................ 20
  3.1 Common law directives .................................................................................................... 20
  3.2 Advance Health Directives ............................................................................................. 21
    3.2.1 Tensions in the debate ............................................................................................ 21
    3.2.2 Consent under an Advance Health Directive ......................................................... 23
    3.2.3 Deciding not to follow an Advance Health Directive ............................................. 24
    3.2.4 Legal uncertainties associated with Advance Health Directives ........................... 25
  3.3 Substitute decision-makers ............................................................................................ 26
    3.3.1 Consistency with good medical practice ................................................................. 27
    3.3.2 Effect of ‘objections’ ............................................................................................... 27
Consent - Summary Points ........................................................................................................ 29
4.0 DECISION-MAKING FRAMEWORK ..................................................................................... 30
  4.1 A collaborative approach ............................................................................................... 30
  4.2 Discussion with families ................................................................................................. 30
    4.2.1 Patients with capacity ............................................................................................. 32
    4.2.2 Patients without capacity ....................................................................................... 33
  4.3 Disclosure and informed consent ................................................................................... 34
    4.3.1 Informed consent .................................................................................................... 35
  4.4 Disputes .......................................................................................................................... 37
  4.5 Resolving disputes .......................................................................................................... 37
  4.6 Decision-making process ............................................................................................... 38
5.0 CLINICAL CONSIDERATIONS ................................................................. 43

5.1 Good medical practice......................................................................... 43
5.2 Resuscitation planning ....................................................................... 44
    5.2.1 Who is suitable for an ARP? ......................................................... 44
    5.2.2 Presumption in favour of resuscitation when there is no documented decision ...... 45
5.3 Cardiopulmonary resuscitation (CPR) ............................................. 46
CPR – Summary Points.............................................................................. 49
5.4 Artificial hydration and/or artificial nutrition .................................... 50
5.5 Assisted ventilation ............................................................................ 51
5.6 Blood transfusions ............................................................................ 52
Clinical Considerations – Summary Points .............................................. 55

APPENDIX 1 ................................................................................................. 56

Part 2 - Ethical and Special Considerations - Table of Contents

APPENDIX 2 ................................................................................................. 58

Excerpt of Speech Hon. R. J. Welford (Attorney-General and Minister for Justice)

APPENDIX 3 ................................................................................................. 59

Possible triggers for initiating an Acute Resuscitation Plan
Executive Summary

In medicine, decisions are made on a daily basis about life-sustaining measures with a primary goal – the preservation of life. However when life cannot be preserved, the task is to provide comfort and dignity to the dying person, and to support others in doing so.

Serious questions must be asked when a patient’s life is being artificially preserved and the treatment leaves them in what could be judged an inhumane or degrading state. Respect for life does not mean that all life must be preserved at all costs.

There are difficult clinical, legal and ethical issues to navigate when deciding whether to withhold or withdraw life-sustaining treatment. When patients plan their end-of-life care in advance, they make the direction clear, for their loved ones and themselves and also for the health professionals who treat them.

Decision-making about life-sustaining medical treatment is less demanding on all those involved if advance care planning starts as soon as possible. Ideally, this will allow patients to make informed choices about issues such as resuscitation planning, and to discuss their wishes with their family1 and friends.

Good medical practice should guide the clinical assessment and treatment options discussed with the patient and/or their substitute decision-maker/s. However, in meeting the standards of good medical practice, medical officers are under no obligation to initiate treatments known to be ineffective, nor to continue with treatments that have become ineffective.

For patients at the end of life, the potential benefits of medical treatment must be weighed against its potential to be burdensome, which might include pain, suffering, compromise of dignity, and loss of independence. In most situations, assessment of the potential benefits and burdens of treatment is based on various levels of probability rather than absolute certainty, and appropriate actions can be unclear to attending staff where advance discussions and decisions have not been made about resuscitation and decisions are required urgently.

Respecting patients’ choices for end-of-life care begins long before the time comes and is an essential component of care for all dying patients. While, ultimately, medical decisions will be made by medical officers, early, frank and honest communication with the patient and their loved ones will avert many potential problems, and also ensure the patient’s wishes for end of life are respected.

All patients, irrespective of age, race, gender, culture or lifestyle, are entitled to the same dignity, compassion and quality of end-of-life care, regardless of whether they have the capacity to make decisions about their health care.

These guidelines have been developed to support Queensland Health’s policy about withholding and withdrawing life-sustaining measures from adult patients. To accommodate the profound complexity in this area, these guidelines start from the premise that decision-making in this area is not, and can never be, straightforward. Therefore in many instances, its guidance offers a less direct approach - by posing questions rather than answers, and considerations rather than formulas. These guidelines contain two parts: the first discusses the legal framework and clinical considerations; the second, ethical and special considerations.

1 Please note: Throughout these guidelines, the word family is often used interchangeably with substitute decision-maker. This is largely for readability purposes, as for the vast majority of cases, the substitute decision-maker will be the next of kin or a close member of the patient’s family. However it is acknowledged that in some cases, the legal substitute decision-maker may or may not be a member of the patient’s family.
Policy Statement

Queensland Health recognises that there are significant and complex clinical, ethical and legal considerations in making decisions to withhold or withdraw life-sustaining measures, even when an adult patient has the capacity to make the decision themselves. Queensland Health also acknowledges that withholding or withdrawing life-sustaining measures will sometimes be in the best interests of an adult patient who does not have the capacity to make the decision. Adult patients with capacity, or those without capacity who have formalised their end-of-life wishes in a valid and enforceable Advance Health Directive, are entitled to refuse medical treatment, even if the withholding or withdrawal of that treatment results in their death.

This policy applies to adult patients without capacity and also adult patients diagnosed with a life-threatening illness or condition, who may not have yet reached the final days and hours of their life. The emphasis in decision-making for patients at the end of life is on advance care planning. This means having discussions as early as possible to minimise the need to determine a patient’s wishes through their substitute decision-maker/s in a crisis-driven situation.

Decisions to withhold or withdraw life-sustaining measures must comply with the standards of good medical practice, be clearly documented, and based on legal requirements for consent from the patient or their substitute decision-maker/s.

Queensland Health principles for decision-making about life-sustaining measures

| Principle 1: | All decision-making must reflect respect for life and the patient’s right to know and choose. |
| Principle 2: | All decision-making must meet the standards of good medical practice. |
| Principle 3: | All efforts must be made to obtain the appropriate consent through a collaborative approach. |
| Principle 4: | There must be transparency in and accountability for all decision-making. |
Summary of key points in the four governing principles

**Principle 1 - All decision-making must reflect respect for life and the patient's right to know and choose.**
- a primary goal of medical care is preservation of life, however, when life cannot be preserved, the task is to provide comfort and dignity to the dying person, and to support others in doing so
- when considering a patient's best interests, several factors must be considered, such as the patient's culture, values and personal wishes
- every patient, irrespective of age, race, gender, culture or lifestyle has the right to dignity and compassion at the end of life
- where the patient lacks capacity to make health care decisions, except in acute emergency situations, consent is required before any life-sustaining treatment can be withheld or withdrawn
- life-sustaining treatment may not be withheld or withdrawn without consent if the doctor in charge of the patient's care knows the adult objects to the withholding or withdrawal of treatment
- consent must always be obtained to withhold or withdraw artificial hydration and/or nutrition
- adults with capacity may refuse medical treatment, even if this is inconsistent with good medical practice.

**Principle 2 All decision-making must meet the standards of good medical practice.**
- good medical practice requires the medical officer and the health care team to adhere to the accepted medical standards, practices and procedures of the medical profession in Australia, and recognises ethical standards by respecting the patient's wishes to the greatest extent possible
- in meeting the standards of good medical practice, medical officers are under no obligation to initiate treatments known to be ineffective, nor to continue treatments that have become ineffective
- in situations where further active treatments may be potentially futile, medical officers must consider whether the proposed treatment will be in the best interests of the patient, and to the greatest extent possible benefit the patient and not cause them harm
- in assessing a patient's best interests, decisions should not be based on whether the health care team, or the patient's relatives or carers would wish to have the treatment themselves if they were in that situation.

**Principle 3 All efforts must be made to obtain the appropriate consent through a collaborative approach.**
- families and healthcare professionals have an obligation to work together to make compassionate decisions for patients who lack decision-making capacity, taking into account previously expressed patient wishes where they are known
- some patients may have expressed their future health care wishes in an Advance Health Directive
- an Advance Health Directive is triggered only when an adult no longer has the capacity for decision-making about matters covered by the directive
- legally, valid Advance Health Directives take precedence over treatment requests made on behalf of the patient by family members, including next of kin
- if consensus cannot be reached about a decision or if the substitute decision-maker/s refuses to comply with the Health Care Principle (see Glossary), the Adult Guardian should be consulted to resolve any dispute.

**Principle 4 There must be transparency in and accountability for all decision-making.**
- meticulous documentation of all decision-making about withholding and withdrawing life-sustaining measures is critical and required by law
- where appropriate, patients should be encouraged to formalise their end-of-life wishes by completing Advance Health Directives
- an Acute Resuscitation Plan form or NFR Orders do not provide legal consent to withhold or withdraw life-sustaining measures.
1.0 INTRODUCTION

These implementation guidelines provide a basis for making decisions about withholding and withdrawing life-sustaining measures. They are built on a framework of current legal, clinical and ethical considerations. The scope of these guidelines is adult patients at or nearing the end of life. They include guidance for decision-making for patients without capacity, as well as patients with capacity.

These guidelines are divided into two parts - Part 1 – Legal Framework and Clinical Considerations and Part 2 – Ethical and Special Considerations (see Appendix 1 for table of contents of Part 2). There are six main chapter areas in this part of the guideline - legislative framework, consent, decision-making framework, clinical decision-making, special considerations, and care for patients at the end of life. The guidelines are divided into two parts primarily for readability purposes, however, both parts should be considered equally in decision-making about withdrawing or withholding life-sustaining measures.

The implementation guidelines are also part of the suite of documents around life-sustaining measures. The documentation hierarchy is represented below:
2.0 LEGISLATIVE FRAMEWORK

2.1 Queensland Legislation

Decisions about life-sustaining measures are medically and ethically challenging. This is the case in Queensland, in other jurisdictions in Australia, and elsewhere in the world.

If an adult has the capacity (see Section 2.4) to make decisions about withholding or withdrawing life-sustaining treatment, the law is reasonably clear. If a valid Advance Health Directive is in place, the law is also reasonably clear, as it is a legally binding document made at a time when the person had the capacity for such decisions. If a patient has capacity, their wishes for medical treatment must be followed. There is a well-established legal principle in Australia that an adult with capacity can refuse any medical treatment, even if it results in their death.

If an Advance Health Directive (see Section 3.1 for more information) is in place, any substitute decision-maker/s appointed under the directive (called a health attorney) has the power to make decisions on behalf of the patient. If an Advance Health Directive is not in place, a substitute decision-maker/s or the Adult Guardian makes decisions on behalf of the patient. The effect of the legislation is that there is always someone to represent the interests of a patient who does not have capacity.

Uncertainty is amplified when patients do not have the capacity to make decisions about their ongoing medical treatment. In these cases, there are two sources of law relevant in deciding whether to withhold or withdraw life-sustaining measures. The first is through common law and the powers of the Supreme Court under its parens patriae jurisdiction. The second through three key statutes:

1. Powers of Attorney Act 1998 (Qld)
2. Guardianship and Administration Act 2000 (Qld)
3. Criminal Code 1899 (Qld)

The legal processes within these three statutes are triggered when a patient loses capacity and decisions about life-sustaining measures are required.

The complex interplay of provisions within the three statutes makes it difficult to navigate a clear path and provide a simple, straightforward policy for decision-making in this area. Decision-making about life-sustaining measures operate differently according to the individual circumstances of the case, such as:

- whether an urgent decision is required
- if a patient has capacity
- whether the patient is terminally ill
- whether the patient requests treatment or refuses treatment
- whether the patient sets out their decisions in an Advance Health Directive
- whether the patient appoints a substitute decision-maker/s.

It is widely acknowledged that the legislative framework in Queensland is complex and in need of review. As it stands, three important aspects arise according to the circumstances of the case:

---

1. whether the relevant medical treatment is a ‘life-sustaining measure’
2. who can make a decision to withhold or withdraw this treatment
3. whether such a decision should be made.

The law operates differently if the clinical decision is to provide life-sustaining measures, rather than withhold or withdraw them. Generally, except in the case of an emergency where it is not practicable to obtain consent, it is at common law a battery to administer medical treatment to a person without their consent.

Under Queensland’s legislation, urgent decisions to commence and continue medical treatment can be carried out without consent, provided reasonable efforts have been made to contact the patient’s substitute decision-maker/s. However, if the treating medical officer knows that the patient objects to the treatment, then consent should be obtained as circumstances permit.

If the medical officer decides the patient has limited understanding of why the medical treatment is being provided and as long as the treatment will cause minimal distress to the patient, objections to the provision of medical treatment can be overruled. These provisions are particularly relevant in the case of blood transfusions.

### 2.2 Life-sustaining measures

Queensland’s legislation\(^4\) defines this as follows:

1. A life-sustaining measure is health care intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation.
2. Without limiting subsection (1), each of the following is a life-sustaining measure —
   - (a) cardiopulmonary resuscitation;
   - (b) assisted ventilation;
   - (c) artificial nutrition and hydration.
3. A blood transfusion is not a life-sustaining measure.

The Guardianship and Administration Act 2000 defines a ‘health matter’, for an adult as ‘a matter relating to health care, other than special health care, of the adult’. The Powers of Attorney Act 1998 includes a similar definition. Under both Acts, a decision about the withholding or withdrawal of a life-sustaining measure is a health matter, rather than a special health matter.

Life-sustaining measures may be withheld or withdrawn without consent only in exceptional circumstances, such as acute emergency situations, and only where the medical officer responsible for the patient’s care is not aware that the patient has made it clear that he or she ‘wanted everything done’ in the event that they lost capacity (in other words, that they have objected to the withholding or withdrawal of medical treatment).

The guardianship legislation also provides for decisions about the withholding or withdrawal of a life-sustaining measure from an adult to be made in accordance with:

- (a) an Advance Health Directive made while he or she had capacity or,
- (b) with the consent of the person’s substitute decision-maker/s.

\(^4\) Powers of Attorney Act 1998 (Qld) & Guardianship and Administration Act 2000, sch. 2, s. 5A
Because the withholding or withdrawal of a life-sustaining measure is a health matter, decision-making about it is generally governed by section 66 of the Guardianship and Administration Act 2000. That section provides:

66 Adult with impaired capacity — order of priority in dealing with health matter

(1) If an adult has impaired capacity for a health matter, the matter may only be dealt with under the first of the following subsections to apply.

(2) If the adult has made an Advance Health Directive giving a direction about the matter, the matter may only be dealt with under the direction.

(3) If subsection (2) does not apply and the tribunal has appointed one or more guardians for the matter or made an order about the matter, the matter may only be dealt with by the guardian or guardians or under the order.

[Editor’s note—If, when appointing the guardian or guardians, the tribunal was unaware of the existence of an enduring document giving power for the matter to an attorney, see section 23 (Appointment without knowledge of enduring document), particularly subsection (2).]

(4) If subsections (2) and (3) do not apply and the adult has made one or more enduring documents appointing one or more attorneys for the matter, the matter may only be dealt with by the attorney or attorneys for the matter appointed by the most recent enduring document.

(5) If subsections (2) to (4) do not apply, the matter may only be dealt with by the statutory health attorney.

(6) This section does not apply to a health matter relating to health care that may be carried out without consent under Division 1.

The effect of section 66 is that a person’s substitute decision-maker/s may make a decision about the withholding or withdrawal of a life-sustaining measure only if the person does not have a valid and enforceable Advance Health Directive that gives a direction about the matter. The Guardianship and Administration Act 2000 also includes a provision that authorises a health provider, in limited circumstances (for example, acute emergencies) to withhold or withdraw a life-sustaining measure without consent (Further detail is contained in Section 3 – Consent).

Because the legislation does not limit life-sustaining measures to those expressly identified, a number of others qualify under this definition. Drug therapies such as chemotherapy, corticosteroids, antibiotics, renal and liver failure treatments (for example, haemodialysis, peritoneal dialysis, haemofiltration) would all qualify as life-sustaining measures. In certain clinical situations, complex surgical procedures could meet the definition of a life-sustaining measure, as could an aspirin tablet.

If the effect of the medical treatment is to immediately save the life of the patient, it is likely to be captured by the definition of a life-sustaining measure. For more detail on the life-sustaining measures identified in the definition, see Section 5 in Part 1 of these guidelines.

2.3 Good medical practice

Decisions to withhold or withdraw life-sustaining measures should reflect the standards of good medical practice for the patient at that time and location, based on thorough clinical assessment. The clinical responsibility for decisions about withholding or withdrawing life-sustaining measures rests with the senior medical officer responsible for a patient’s care. Accepted ethical principles should be taken into account when considering what good medical practice is in any particular situation. For more detail, see Part 2 - Ethical and Special Considerations.
However, for patients assessed to have capacity to make decisions about health matters, it is important to recognise they may refuse medical treatment, including the range of life-sustaining measures, even if this results in their death. In other words, the decision of a patient who has capacity to refuse medical treatment can be inconsistent with what would be considered good medical practice. This is an area where the tension between patient autonomy and good medical practice requires careful and sensitive discussions, decision-making and documentation.

The *Guardianship and Administration Act 2000* defines good medical practice as that which applies to the Australian medical profession, having regard to recognised ethical and professional standards, practices and procedures. Medical officers should consider the professional practice standards that apply to the profession as a whole, and where relevant, practice standards which apply to their specialty.

Section 3.12 of the Australian Medical Council’s Good Medical Practice: a Code of Conduct for Medical Officers in Australia (the AMC Code) applies to end-of-life care and states:

Medical officers have a vital role in assisting the community to deal with the reality of death and its consequences. In caring for patients towards the end of their life, good medical practice involves:

i. Taking steps to manage a patient’s symptoms and concerns in a manner consistent with their values and wishes.

ii. Providing or arranging appropriate palliative care.

iii. Understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient.

iv. Understanding that you do not have a duty to try to prolong life at all cost. However, you do have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that your patients receive appropriate relief from distress.

v. Accepting that patients have the right to refuse medical treatment or to request the withdrawal of treatment already started.

vi. Respecting different cultural practices related to death and dying.

vii. Striving to communicate effectively with patients and their families so they are able to understand the outcomes that can and cannot be achieved.

viii. Facilitating advance care planning.

ix. Taking reasonable steps to ensure that support is provided to patients and their families, even when it is not possible to deliver the outcome they desire.

x. Communicating bad news to patients and their families in the most appropriate way and providing support for them while they deal with this information.

xi. When your patient dies, being willing to explain, to the best of your knowledge, the circumstances of the death to appropriate members of the patient’s family and carers, unless you know the patient would have objected.

### 2.4 Capacity

Queensland’s legislative framework for withholding and withdrawing life-sustaining measures is triggered by whether a person has the capacity to make decisions about health matters.

**Under the General Principles (see Glossary), an adult patient is presumed to have capacity.**

---

5 The ‘good medical practice’ test does, however, apply to the directions in an Advance Health Directive (further discussion of this in Section 3.2.4 – Legal uncertainties associated with Advance Health Directives).

2.4.1 Competency and capacity

Although the terms ‘competence’ and ‘capacity’, are often used interchangeably, there are important differences between them. ‘Competence’ and ‘incompetence’ are legal designations determined by courts and judges, whereas decision-making capacity is clinically determined by physician assessment. Under Queensland legislation, all adults are presumed legally competent unless determined incompetent judicially. An adult who possesses legal competence, however, may lack the capacity to make specific treatment decisions. Therefore a patient’s capacity is determined by a clinician’s evaluation rather than by the court’s.

2.4.2 Assessing capacity

Lack of capacity cannot be established merely by reference to age, cultural background, behaviour, appearance or physical condition, as this may lead to unjustified assumptions about a patient’s competence or capacity to give informed consent. Therefore, every patient should be cared for as a unique individual, and should never be labelled ‘incapacitated’ or a ‘vegetable’ as a result of a particular medical condition or diagnosis.

Any question as to whether a person lacks capacity to give informed consent will be decided by the medical officer responsible on the balance of probabilities. This is consistent with good medical practice.

Despite the widespread use of capacity assessments, there is no consensus on generic criteria for capacity assessment. Moreover, several studies have demonstrated difficulties when clinicians tend to rely on informal clinical impressions when assessing a patient’s capacity to consent to treatment. Therefore a multi-dimensional approach should be adopted. This could include:

- discussions with the patient’s family
- consultation with other health professionals
- communicating with the patient with the support of toolkits, including pictures or flash cards. (These may be available through social workers or community liaison officers).

Specialists or more senior medical officers should be consulted where doubt exists about a patient’s capacity.

An assessment of capacity is not based on the test: ‘Would a rational person decide as this person has decided?’ Rather, the thought processes behind the decision are relevant to the question of capacity. A person is incapacitated if he or she is incapable of acting on, making decisions, communicating decisions, understanding decisions or retaining the memory of decisions due to a mental disorder or a physical disability that prevents communication.

Capacity depends on the nature of the task for which assessment is required, such as decisions about health matters. How well the patient functions will also require consideration of the nature of the decision to be made as well as the clinical condition of the patient.

It is generally held that there are four functional abilities used in capacity assessments:

1. the ability to express a choice
2. the ability to understand information relevant to treatment decision-making

---

7 Jones, R. & Holden T. 2004. p. 971
3. the ability to appreciate the significance of that information for one’s own situation, especially concerning one’s illness and the probable consequences of one’s treatment options

4. the ability to use relevant information to reason so as to engage in a logical process of weighing up the treatment options

Patients’ status on these abilities is not an all-or-none matter. Rarely can it be said that a patient does or does not possess one of these abilities. Usually patients manifest all of them, but in varying degrees. The question becomes whether a patient functions sufficiently in these areas of ability to allow a judgement that he or she has capacity to consent to medical treatment.

Generally, a patient can be regarded as having decision-making capacity if they meet the following five criteria:

1. Does the patient understand the basic medical situation?
2. Does the patient understand the nature of the decision being asked of him or her? Understanding includes the following:
   - implications – benefits, risks, what the treatment entails
   - alternatives and their implications, including the implication of no decision
   - retaining the information (short-term memory function).
3. Can the patient use or weigh that information as part of the process of making the decision? (for example, asking questions)
4. Can the patient communicate a decision? (for example, by talking, using sign language or any other means)
5. Is the patient communicating the decision voluntarily? (for example, is there an absence of coercion, undue influence or intimidation by the patient’s family/decision-maker/s).

2.4.3 Patients with borderline or fluctuating capacity

Where patients have borderline or fluctuating capacity, it can be difficult to assess if the individual can make valid decisions on very serious issues. For example, a patient may be capable of making decisions about daily life, such as where they live or what they wear, but may not be able to understand the implications of proposed medical interventions or medications. Psychiatric evaluation of a patient’s capacity for decision-making about health matters may be considered where consensus cannot be reached within the health care team. Further detail on capacity assessment as it relates to life-sustaining measures can be found in the associated Clinical Guideline – Capacity Assessment.

Law and good medical practice require that as little interference as possible occurs with a person’s right to make autonomous decisions about health matters. Some limits on this right, however, are legally and ethically justified when individuals with mental conditions that impair their decision-making are likely to suffer harm if their choices are followed. However it is important to recognise that not all people suffering from a mental disorder lack the capacity to make decisions about their health care. (For more information, see Part 2 – Ethical and Special Considerations – Mental health patients)

2.5 Emergency situations

The legislation distinguishes consent provisions for withholding or withdrawing medical treatment depending on whether the patient requires urgent health care. For example, consent
is not required to provide urgent health care, as long as the medical officer is not aware of any objections made by the patient to the treatment provided.\textsuperscript{11}

The Guardianship and Administration Act 2000 has different provisions depending on whether the medical treatment comes under health care, urgent health care or an acute emergency.

Schedule 2 of the Guardianship and Administration Act 2000 provides that ‘health care of an adult includes withholding or withdrawal of a life-sustaining measure for the adult if the commencement or continuation of the measure for the adult would be inconsistent with good medical practice.’ In other words, if administering the medical treatment would be considered futile and would provide no benefit to the patient. Futile treatment is discussed in Part 2 - Ethical and Special Considerations.

\subsection*{2.5.1 Acute emergencies}

Acute emergencies are characterised by the urgent need to make treatment decisions to maintain the patient’s life and health. They may occur in any clinical setting.

\textbf{Providing life-sustaining measures in acute emergency situations}

Legal consent provisions for administering urgent medical treatment to an adult patient who lacks capacity are not as stringent as they are to withhold or withdraw treatment. In providing life-sustaining measures to a patient without capacity, the legislation recognises that it is not always practical to obtain consent in urgent health care situations.\textsuperscript{12}

Cardiopulmonary resuscitation (CPR) as a life-sustaining measure is regarded as an acute emergency in all cases. If it is good medical practice to provide CPR, a medical officer may attempt resuscitation on a patient without obtaining consent, provided they know the patient does not object to having CPR. ‘Knowing’ in this context would be where the medical officer is aware of the patient’s refusal of CPR through:

- direct knowledge (rather than hearsay, for example, from a family member) through a conversation recently held with the patient
- directions in a patient’s Advance Health Directive, if they have one
- the patient’s wishes as documented in the progress notes
- instructions in the patient’s current Acute Resuscitation Plan.

However, even if the medical officer knows the patient objects to CPR, there are legal provisions that enable medical officers to override objections. For example, if the patient has minimal understanding of what is entailed with providing CPR and in the medical officer’s opinion they would suffer temporary or no distress, this would be sufficient grounds to override their objection. A second opinion should be sought in these cases.

\textbf{Withholding or withdrawing life-sustaining measures in acute emergency situations}

If the patient objects to withholding medical treatment, for example, the patient requests the medical officer to ‘do everything possible’ or communicates the message ‘don’t let me die’ before losing capacity, then consent from the patient’s substitute decision-maker/s would be required if the clinical decision is to not provide medical treatment. (See following page for further information about the effect of ‘objections’ in acute emergency situations.) The substitute decision-maker is required to make decisions in the patient’s best interests.

All reasonable efforts to obtain consent should be made, however in some emergency situations it may be inappropriate to continue to maintain life while attempts are made to obtain consent to withhold or withdraw treatment.

\textsuperscript{11} S. 63 Guardianship and Administration Act 2000
\textsuperscript{12} S.63 Guardianship and Administration Act 2000
Life-sustaining measures in an acute emergency –

Effect of objection under s63A(2)

(S63A Guardianship and Administration Act 2000)

Generally, CPR can be withheld from a patient without needing to obtain a substitute decision maker’s consent if the treating doctor reasonably believes that -

1. the patient has impaired capacity **AND**
2. commencing CPR would not be good medical practice **AND**
3. the decision to withhold CPR needs to be made straight away.

- the only time consent would be required to withhold CPR is where the treating doctor directly knows that the patient objects to withholding CPR.
- the only way a clinician can "directly know" a patient objects is if
  a) the patient is able to articulate this to the treating doctor or nurse (such as a patient saying "do everything possible" or "don’t let me die" at the time of presentation to the hospital or facility), or
  b) this is written in a patient's Advance Health Directive, the patient's chart or the Patient Choices section of the ARP as applying to the particular circumstances (and such a statement is still valid, remembering that a statement to this effect which differs from the resuscitation plan should be escalated and preferably be resolved before the resuscitation plan needs to be implemented), or
  c) the patient's conduct makes it clear that they want CPR.

Due to these limitations, a "known" objection should not arise regularly. A family member saying that the patient would want everything done does not constitute an objection by the patient, as the treating doctor cannot (without more information or a direct indication from the patient themselves) KNOW if this is true and accurate.

If there is an objection which the doctor directly knows about, there may be a window of opportunity to obtain the consent required to withhold CPR, from a substitute decision maker (including the Adult Guardian). The substitute decision maker must make their decision in the patient's best interests. If there is no time to obtain consent, then CPR will need to be commenced, and consent obtained to withdrawing of the life-sustaining measures that have been implemented.
Ignoring consent provisions in the legislation has the potential to expose the medical officer to risk of criminal and civil liability if the clinical decision is to not resuscitate the patient. If all reasonable attempts to locate the patient’s substitute decision-maker/s are unsuccessful, the Adult Guardian becomes the decision-maker as a last resort.

**In an acute emergency, if the clinical decision is to withhold life-sustaining measures, consent is not required provided the medical officer is not aware of objections raised by the patient.**

In an acute emergency situation, there is an important legal exception to the consent provisions for some life-sustaining measures: artificial nutrition and/or hydration may not be withheld or withdrawn without consent. The reason for this is that artificial hydration and nutrition under the legislation are not life-sustaining measures in acute emergencies.

Therefore, consent must **always** be obtained to withhold or withdraw artificial hydration and/or nutrition.

### 2.5.2 Non-acute situations

Non-acute situations are included in this section for completeness, and are characterised by more predictable clinical environments where the patient’s condition is considered relatively stable and decisions are not required urgently. Patients who lack capacity in non-emergency situations are typically in a ward, rather than an emergency department or intensive care unit. Examples of this might include a long-term in-patient suffering post-coma unresponsiveness or a patient admitted with end-stage Alzheimer’s Disease. In non-acute emergency situations it is presumed sufficient time is available to locate the patient’s substitute decision-maker/s and discuss the patient’s end-of-life wishes, or to obtain the patient’s Advance Health Directive, should they have one.

Where no urgent decisions are required, consent must always be obtained from the substitute decision-maker/s (or through the patient’s valid Advance Health Directive) to withhold or withdraw medical treatment from a patient without capacity.

In non-acute emergencies where a patient lacks capacity and their substitute decision-maker/s insists on non-standard forms of treatment (including extraordinary measures), that in the considered opinion of the medical officer in charge is not in the patient’s best interests and inconsistent with good medical practice, there are essentially two choices, that will be governed by the circumstances:

1. The medical officer is not obliged to continue treating the patient, but must immediately refer the patient’s substitute decision-maker/s to another senior medical officer experienced in that area of medicine.
2. The matter can be referred to the Office of the Adult Guardian for a determination of the case.

For further information on communicating with patients and their families, see *Part 1 - Section 4*.

### 2.6 Transparency and accountability

Ensuring open and frank communication between the health care team and the family/substitute decision-maker/s of the patient will limit the situations where medical officers are asked to provide what would constitute potentially futile treatment (see Ethical and Special Considerations in Decision-Making for Withholding and Withdrawing Life-Sustaining Measures from Adult Patients).
Decisions to withhold and withdraw life-sustaining measures made solely on clinical grounds must be strongly justified and thoroughly documented. Careful attention to recording (in the charts and progress notes) details of the clinical circumstances and events leading up to the decision to withhold medical treatment is required by law. It is highly recommended that a second opinion from another senior medical officer/consultant be obtained in cases where the patient or their family insists on ‘everything to be done’ and it is not considered good medical practice to do so.

Meticulous documentation of all decision-making regarding the withholding and withdrawing of life-sustaining measures is required by law.\textsuperscript{13}

The decision-making process must be fully documented and all details included in the patient’s medical record, including:

- the patient’s condition and the rationale for withholding or withdrawing life-sustaining measures
- documentation of the patient’s consent if they have capacity
- the rationale for not obtaining consent in an acute emergency
- matters discussed with the patient’s family, close friends and carers
- details of the substitute decision-maker/s and the decisions made by the substitute decision-maker/s
- details of the medical staff involved in the decision-making.

Junior medical officers, while encouraged to participate in end-of-life discussions, must be supervised by more senior medical officers in decisions to withhold or withdraw life-sustaining measures.

2.6.1 Documentation/process audit post-death

All decisions to withhold or withdraw life-sustaining measures should be reviewed by the senior medical officer responsible for the patient’s care (and/or consultant if applicable) within five working days post-death. It is recommended that consideration be given to reviewing documents and decision-making by the health care team during the Level 1 Mortality Screening Review (Health Quality and Complaints Commission Act 2006 [Qld]).

2.6.2 Acute Resuscitation Plans (ARP)

The introduction of a formal substitute decision-making scheme in the Guardianship and Administration Act 2000 has confirmed that ‘Not for Resuscitation’ (NFR) Orders have no legal status and cannot be relied upon in the absence of other forms of consent to withhold or withdraw medical treatment. Therefore, NFR Orders or ‘Do Not Resuscitate Orders’ legally cannot be used as valid consent to any proposal to withhold or withdraw life-sustaining treatment.

NFR Orders have been replaced by a standard Acute Resuscitation Plan (ARP) form, which has been developed in consultation with clinicians. The ARP form was piloted in six hospitals for six weeks in May-June 2009 and implemented in all Queensland Health facilities in 2010.

The ARP form provides for consistent documentation of clinical recommendations to withhold or withdraw life-sustaining measures, including CPR and assisted ventilation. In conjunction with these guidelines, the ARP form is also intended to prompt discussion with patients and/or their substitute decision-maker/s about resuscitation planning in the event of an acute event, such as cardiac or respiratory arrest. An ARP can be valid for the current admission, until a specified future date or for the current and subsequent admissions. A Cover Sheet has been developed to manage copies of ‘active’ ARPs for patients transferred between health facilities.

\textsuperscript{13} S. 66B(2)(a) & (b) Guardianship and Administration Act 2000
and during transit. The Cover Sheet advises receiving health care facilities of the existence and purpose of the patient’s active ARP.

As with NFR Orders, the ARP is not a legal document, nor does it substitute for legal consent; it is a clinician’s record, and provides clinical authority to act when urgent decisions are required. However, it formalises an important part of advance care planning from the clinical perspective, and, therefore, facilitates improved decision-making and outcomes for patients at the end of life.

2.6.3 Reviewing ARPs and Advance Health Directives

While ARPs focus on resuscitation planning, they represent only a small part of advance care planning. Ideally, a certified copy of the patient’s valid Advance Health Directive should be included in the accompanying documentation (see Section 3.1 for more information on Advance Health Directives).

If a patient is transferred with an ARP from another facility, the ARP should be reviewed and if necessary rewritten on admission. Documentation should involve reviewing the patient’s Advance Health Directive, in line with their condition and other clinical indicators. Where new treatments become available, or a patient’s circumstances change, the patient should be encouraged to update their Advance Health Directive.

2.6.4 Protections for health professionals

Health providers are afforded a number of protections under the legislation. When they act in good faith and where the standards of good medical practice have been followed, the legislation recognises this. For example, health providers are protected if they act on a health care decision by a substitute decision-maker and it subsequently emerges that the person does not have the power to make such decisions.\(^\text{14}\) In addition, they are protected if they act in reliance on an Advance Health Directive without knowledge of its invalidity, or they are not aware that an Advance Health Directive exists. In these circumstances, health providers should seek indemnity from Queensland Health if they are subjected to civil or criminal liability.

While the law does offer protections if medical officers override the directions in an Advance Health Directive, this must be done on grounds of good medical practice, and the medical officer may be required to defend his or her position (see Section 3.2.3 Deciding not to follow an Advance Health Directive).

\(^{14}\) Section 77, Guardianship and Administration Act 2000
General

1. The legal processes are triggered when a patient loses capacity and decisions about life-sustaining measures are required.
2. The law operates differently if the clinical decision is to provide life-sustaining measures, rather than withhold or withdraw them.
3. Life-sustaining measures may be withheld or withdrawn without consent only in exceptional circumstances such as acute emergency situations, and only where the medical officer responsible for the patient’s care is not directly aware that he or she ‘wanted everything done’ in the event capacity is lost.

Capacity

4. In Queensland, an adult is presumed to have capacity. Lack of capacity cannot be established merely by reference to age, cultural background, behaviour, appearance or physical condition, as this may lead to unjustified assumptions about a patient’s competence or capacity to provide informed consent.
5. Capacity is not an ‘all-or-none’ concept but depends on the nature of the task for which assessment is required, such as decisions about health matters. Capacity assessments involve more than just judging cognition and weighing objective scores of memory, concentration, attention and orientation.
6. In cases where patients have borderline or fluctuating capacity, it can be difficult to assess whether the individual can make valid decisions on very serious issues. Second opinions must be obtained where doubt exists about a patient’s level of capacity to make decisions about their own health matters.

Emergency Situations

7. In acute emergency situations, medical treatment (with the exception of blood transfusions) may be withheld or withdrawn from an adult without consent if the medical officer in charge of the adult patient’s care reasonably considers:
   - that the patient has impaired capacity, and
   - the commencement or continuation of the measure would be inconsistent with good medical practice, and
   - it is consistent with good medical practice, the decision to withhold or withdraw the measure must be taken immediately.
8. However, life sustaining medical treatment may not be withheld or withdrawn without consent if the medical officer in charge of the patient’s care knows the adult objects to the withholding or withdrawal of treatment.
9. Consent must always be obtained to withhold or withdraw artificial hydration and/or nutrition, even in an acute emergency.
10. The clinical decision to commence CPR is considered an acute emergency in all cases. This means that there may be limited circumstances where consent would be required if it is good medical practice to attempt resuscitation and the medical officer is not directly aware the patient wants to be resuscitated.
3.0 CONSENT

Life-sustaining medical treatment can only be withheld or withdrawn where consent is obtained or where legislative authority is given to make the decision without consent. Where the patient lacks capacity to make health care decisions, except in some acute emergency situations, consent is required before any life-sustaining treatment can be withheld or withdrawn. Known objections by the patient to the provision or withholding of medical treatment can affect the consent provisions. Consent must be obtained through the following, in order:

1. The patient’s valid Advance Health Directive. If none, then:
2. Guardian/s appointed by the Tribunal or Order of the Tribunal.\(^{15}\) If none, then:
3. Attorney/s appointed under most recent enduring document. If none, then:
4. A statutory health attorney/s. If none, then;
5. The Adult Guardian.

3.1 Common law directives

While Advance Health Directives formalise the statutory approach by documenting health care decisions to come into effect at a time when a person no longer has capacity for decision-making, informal health directives are also recognised.\(^{16}\) As an extension of the right of self-determination, the common law recognises the right of every competent adult to indicate in advance whether or not he or she consents to particular medical treatment.\(^{17}\) There are no specific formal requirements for making an advance decision at common law, such as a requirement for putting the decisions in writing. Such matters will, however, go to the weight of evidence in determining whether a valid and applicable advance decision has been made. This means that the discussion or discussions held between the patient and his or her substitute decision-maker/s will need to be recalled at the time the decisions are made.

The recognition of common law directives in addition to a statutory scheme providing for advance health directives may also create uncertainty and create a two-tiered system where different laws apply to the two types of advance directives without any real justification for those differences.\(^{18}\) Further, if an adult who has capacity expresses a view about his or her end-of-life health care, but the view is not expressed in a way that complies with the requirements for the making of a statutory advance health directive, a health provider would need to decide whether the adult’s previously expressed view (for example, written in a letter or expressed to members of the family) satisfies the common law test. This may be difficult to determine in practice, and the requirement for decision-makers to act in accordance with, and represent, the patient’s best interests should be taken into account. It may be that at the time decisions are required, a Court would expect substitute decision-makers to act in accordance with the General Principles and the Health Care Principle (statutory regime) in communicating the common law directive to the health care team. It should be noted that the law in this area is uncertain and untested in this regard.

It should also be noted that for many people, this approach to advance care planning is more acceptable for many reasons. For example, where families are very close and have common and shared objectives about future health care needs, the need to formalise wishes may not seem necessary. In addition, the length of the prescribed form in Queensland may be a deterrent to completing it.

---

\(^{15}\) Queensland Civil and Administrative Tribunal (QCAT)

\(^{16}\) S. 39 of the Powers of Attorney Act 1998 provides that: This Act does not affect common law recognition of instructions about health care given by an adult that are not given in an advance health directive


3.2 Advance Health Directives

An Advance Health Directive, or advance care directive as it is also known (or living will in other countries such as the UK and US), is a formal document in which an adult provides direction about current and future health matters, and in which they can nominate one or more people to make decisions on their behalf if they become unable. There are provisions in both the Powers of Attorney Act 1998 and the Guardianship and Administration Act 2000 that set out how Advance Health Directives operate generally, and more specifically address decisions to withhold or withdraw life-sustaining measures.

An Advance Health Directive is triggered only when the adult no longer has the capacity for decision-making about health care matters. Further, a direction in an Advance Health Directive to withhold or withdraw a life-sustaining measure cannot operate unless there is a clinical assessment that the adult patient has no reasonable prospect of regaining capacity for health matters. More specifically, the legislation provides that where a patient has an Advance Health Directive in place, a direction to withhold or withdraw life-sustaining measures cannot operate unless the person ‘has no reasonable prospect of regaining capacity for health matters’ and at least one of the following applies to the adult patient:

1. A terminal illness or condition (incurable or irreversible and as a result of which, in the opinion of a medical officer treating the adult and another medical officer, the adult may reasonably be expected to die within one year).
2. A persistent vegetative state (a condition involving severe and irreversible brain damage which, however, allows some or all of the adult’s vital bodily functions to continue, including, for example, heartbeat or breathing).
3. A permanent state of unconsciousness (a condition involving brain damage which, however, allows some or all of the patient’s vital bodily functions to continue, including, for example, heartbeat or breathing).
4. An illness or injury of such severity that there is no reasonable prospect that the patient will recover to the extent that their life can be sustained without the continued application of life-sustaining measures.

Provisions in the same section add that for directions to withhold or withdraw artificial hydration and/or nutrition to be legal, even with consent, the commencement or continuation of the measures must be inconsistent with good medical practice. In other words, the provision of artificial hydration or nutrition would be of no benefit to the patient and any attempt to administer these measures would constitute clinically futile treatment.

3.2.1 Tensions in the debate

As with many matters involving health care choices, there are controversies and tensions in the debate about whether Advance Health Directives can truly represent an adult’s wishes for care at the end of life. Partly this has to do with the directions not being contemporaneous at the time the decisions are needed. Yet community support in favour of people having the ability to make health care decisions in anticipation of a future time when they lose capacity is often reported in the media.

Research also indicates that there is support for enabling adults to make Advance Health Directives in relation to end-of-life care:

The desire for greater involvement in decision-making on health issues is even more pronounced in relation to the area of terminal care. Australian opinion polls show that community attitudes are moving strongly towards wanting more control over the terminal stage of life, and

---

19 Powers of Attorney Act 1998 (Qld), s. 36 (2)(c)
20 Powers of Attorney Act 1998 (Qld), s. 36 (2)(a)(i)
21 Powers of Attorney Act 1998 (Qld), s. 36 (2)(b)
the Public Health Association of Australia supports legislation to allow people to prepare enforceable living wills rejecting excessive medical treatment in the event of terminal illness.\textsuperscript{22}

However, it should also be noted that the use of Advance Health Directives in relation to the withholding and withdrawal of life-sustaining measures has also been criticised. Given the irreversible consequences involved, there is a view that Advance Health Directives are potentially an inadequate tool to reflect accurately the wishes of an adult at the time when the health care is to be withheld or withdrawn. One of the tensions is the perception that advance health directives are open to abuse, with vulnerable persons potentially being pressured into completing advance health directives to refuse life-sustaining measures. It has also been suggested that this pressure may be in the form of direct coercion from a person close to the adult, but may also be in the form of ‘social’ pressure:\textsuperscript{23}

For people with disability, the social pressure not to be a ‘burden’ can be great and, in the absence of other protective measures which guard against both overt duress on an individual and the more general social coercion, people with disability may believe they have an obligation to die.

This view raises concerns about the appropriateness of justifying the use of Advance Health Directives for the withholding or withdrawal of life-sustaining measures in terms of patient autonomy. Other suggested problems with using Advance Health Directives for decisions in relation to life-sustaining measures include:\textsuperscript{24}

- the low numbers of people who actually execute advance directives
- the reality that often people are ‘not provided with enough information about illnesses and treatments to make prospective life-or-death decisions about them’
- evidence suggesting that people can change their treatment preferences over short periods of time
- the problems of locating and interpreting the advance directive at the relevant time.

On the other side of the debate, while acknowledging these concerns, some observers are of the view that the right to make an Advance Health Directive should be retained.\textsuperscript{25} \textsuperscript{26}

The fact that most people have not made an advance directive does not mean that they do not want the right to make one. Many of the important civil rights in Australia are never exercised by the majority of the population but they are fundamental rights which Australians expect to have access to if needed, for example, rights to trial, rights to freedom of movement and rights to protest. The right to make an advance directive is also a fundamental right and for that reason it is worthy of our respect.

Advance Health Directives about withholding and withdrawal of life-sustaining measures are recognised as an important component of advance care planning generally, in which informed discussions about treatment preferences for end-of-life care can take place between patients, family and clinicians. People may wish to put these measures in place to relieve family members of the potential burden of life-or-death decision-making on their behalf in the event that they later lose capacity.

3.2.2 Consent under an Advance Health Directive

An Advance Health Directive is a legally recognised expression of the patient’s wishes in relation to future health care decisions. An Advance Health Directive must be:

1. A written document; and
2. Signed by the adult patient (or by an ‘eligible signer’ on the adult’s behalf); and
3. Signed and dated by an ‘eligible witness’ and certified that the document was signed in their presence and the adult appeared to them to have capacity; and
4. Signed and dated by a medical officer (not the witness) and certified that the adult appeared to the medical officer to have capacity to make the Advance Health Directive.

The health care team is entitled to sight the original or certified copy of the Advance Health Directive.

It is the responsibility of the person making an Advance Health Directive to make sure the decisions in their document will be drawn to the attention of health care professionals when it is needed at a future time. Certified copies of the Advance Health Directive may be held at the hospital where the patient is being treated, in the medical records of the patient’s general practitioner, in the possession of a close relative, or at the person’s own residence. Some people may also carry a card or wear a bracelet with information to this effect.

An Advance Health Directive is not applicable in the situation where the patient has or regains capacity. If a patient regains capacity, if they wish, they can revoke previous directions.

An Advance Health Directive should not be relied upon in any of the following circumstances:

- if the document is obviously defective (such as pages missing, not signed, dated or witnessed)
- if there is doubt about the directions themselves (for example, terminology or treatment pathology)
- if the directions are uncertain or inconsistent with good medical practice
- if the proposed treatment is not the treatment specified in the Advance Health Directive
- if the circumstances are different from those that have been set out in the advance decision
- if the person withdrew the decision while they still had capacity to do so
- if personal or medical circumstances have changed to the extent that the direction to withhold or withdraw life-sustaining measures is no longer appropriate
- if the person has done something that clearly goes against the advance decision which suggests they have changed their mind.

It is also important to establish that the person making the Advance Health Directive was 18 or older when they made their decision and that they had capacity to do so.

If the Advance Health Directive is deemed not to be valid, the statutory consent process must be followed, that is, using the patient’s substitute decision-maker/s.

If it is established that the Advance Health Directive is valid, the directions must not only be respected, but followed, as it is a legally binding document, acting as the patient’s decision-maker/s when they lose capacity. Since the effect of the document is of the adult patient making health care decisions while they had capacity, they are entitled to refuse any medical treatment. Legally, valid Advance Health Directives take precedence over treatment requests made on behalf of the patient by family members.

---

Note that there are some exceptional situations where medical officers can choose not to follow the directions in an Advance Health Directive. See following section 3.2.3 for more detail.
The treating medical team must always start from the assumption that the person had the capacity to make the advance decision, but even in emergency situations, as far as practicably possible, medical staff must ensure that the Advance Health Directive is a valid document.

To be applicable, directions in an Advance Health Directive must apply to the situation in question and in the current circumstances. However it should be noted that objections to certain forms of treatment can be made at a previous time, and must also be taken into consideration in the decision-making process. Health care professionals must first determine if the person still has capacity to accept or refuse treatment at the relevant time. If they have capacity, they can refuse treatment at this point, or they can change their decision and accept treatment. In deciding whether an advance decision applies to the proposed treatment, the medical officer responsible for the patient’s care must consider:

- the date of the Advance Health Directive, the patient’s clinical circumstances and whether the advance decisions relate to those circumstances, and
- whether there have been any changes in the patient’s personal life (for example, the person is pregnant and this was not anticipated at the time of the advance decision) that might affect the validity of the advance decision, and
- whether there have been any developments in medical treatment that the person did not foresee (for example, new medications, treatment or therapies), and
- if any prior objections to health treatment have been made in any capacity. These objections must be taken into consideration in all decision-making about providing or not providing medical treatment, and
- whether a patient may have included in their Advance Health Directive that they consent to withholding or withdrawal of life-sustaining measures despite the objection at the time this is occurring. This must be respected.

Note also that under the legislation Advance Health Directives do not have a time-limit despite the recommendation on the prescribed form the document should be reviewed every two years. Revoking an Advance Health Directive ‘may’ be done in writing while the person still has capacity. There is no specific or prescribed form for revoking an Advance Health Directive as there is for an Enduring Power of Attorney.

It is Queensland Health’s policy that certified copies of Advance Health Directives are permitted in certain circumstances. Clinical and administrative personnel may certify a photocopy or facsimile of an original Advance Health Directive to keep on the patient’s records. This may also be useful when transferring patients between facilities. However it should be recognised that this does carry an element of risk. For example, the patient may revoke the copied Advance Health Directive and make a new one some months later and neglect to inform the hospital when they are admitted. Despite this, it is acknowledged that in many circumstances when immediate decisions are required, file copies of Advance Health Directives may be the best indication of a patient’s wishes. Even if the Advance Health Directive later proves to be ‘invalid’, it would still comply with common law evidentiary provisions.

### 3.2.3 Deciding not to follow an Advance Health Directive

If, after careful consideration, a medical officer chooses not to follow a patient’s Advance Health Directive, a second opinion must be sought from another senior medical officer or consultant. Meticulous and thorough record-keeping will be required in these circumstances. Utmost care should be taken in this area because, while the law does offer some protections for not following the directions in a valid Advance Health Directive, there are risks if medical officers choose not to do so.

---

28 This would include whether the document is an original document, rather than a photocopy or facsimile.
29 S.103 Powers of Attorney Act 1998 permits medical officers to override directions in an Advance Health Directive if the directions are inconsistent with good medical practice. This particular section offers statutory protection for such decisions.
Generally, medical officers are protected in circumstances where:

- they act in reliance on an Advance Health Directive without knowledge of its invalidity, or
- they act without knowledge of the existence of an Advance Health Directive, or
- they fail to act in accordance with an Advance Health Directive that is uncertain, inconsistent with good medical practice or that they otherwise consider is inappropriate due to circumstances changing since the directive was made.

However, the onus of proof of ‘uncertainty’ would be on the medical officer who may be required to defend this position in a court of law. Therefore the need to clearly document these circumstances cannot be overstated.

### 3.2.4 Legal uncertainties associated with Advance Health Directives

Some legal commentators\(^{30}\) have raised the issue that Advance Health Directives in Queensland have a different status to a common law directive for advance health directions. This largely concerns the tension between the principles of self-determination and the sanctity of life.

A patient’s right to self-determination underpins the principle of autonomy and patients who complete an Advance Health Directive are entitled to assurances that their decisions for end-of-life care, in particular withholding or withdrawing medical treatment, will be followed. In circumstances where the directions in an Advance Health Directive are overturned on the basis of uncertainty, inconsistency with good medical practice, or where the patient is not sufficiently ill for the directions to apply, it is Queensland Health’s policy that the decision-making responsibility will fall to the decision-maker/s nominated as health attorney in the document, in the event the patient loses capacity.

Because Advance Health Directives operate only when the person is terminally ill and can be overturned on the basis of good medical practice, they potentially have a different status to common law directives. The following quote is provided in the context of law reform that is being sought in this area.

\[\text{At common law, an advance directive can operate only if it is valid. The courts scrutinise the circumstances of each case very carefully to ensure that the adult possessed the requisite competence and that undue influence had not been exercised. Further, the courts go to great lengths to satisfy themselves that a previously given directive is valid, still represents the views of the adult and that the directive was intended by the adult to govern the medical situation that ultimately arose. Once satisfied of these matters, there is no further limitation on when a directive to refuse a life-sustaining measure will operate. It is irrelevant that the adult would have lived for an extended time or even made a full recovery if the life-sustaining measure were given, or that the adult was not suffering from any illness or disease at the time a decision had to be made about treatment. The directive binds a health professional to the extent that it would be unlawful for that professional to provide the treatment that has been refused.}^{31}\]

The Queensland Law Reform Commission is currently reviewing the guardianship legislation. Due to the complexity of this area, this process is expected to take a number of years.

---


\(^{31}\) Ibid., p. 18
3.3 Substitute decision-makers

If an Advance Health Directive is not in place, and it is not an acute emergency, the law is that in every instance, consent is required from a patient’s substitute decision-maker/s before any life-sustaining measure can be withheld or withdrawn. The medical officer responsible for the patient’s care must make all reasonable efforts to contact the patient’s substitute decision-maker/s should the patient not have or lose capacity. Substitute decision-makers are required to exercise power in accordance with the terms of their appointment and the Health Care Principle (see Glossary).³²

If an Advance Health Directive is not in place, the first of the following substitute decision-makers available to give consent will have authority for the patient’s health care decisions:

1. A guardian appointed by the Queensland Civil and Administrative Tribunal or Order of the Tribunal; but if none appointed or made, then:

2. A health attorney appointed under the most recent enduring document (Advance Health Directive or Enduring Power of Attorney); but if none appointed, then:

3. A statutory health attorney, including if no one else is available; then:

4. The Adult Guardian.

A guardian is a person appointed by the Tribunal to exercise power on behalf of the adult. A person who demonstrates they have been duly appointed as guardian can give consent to withhold or withdraw medical treatment. The health care team is entitled to ask the guardian to provide proof of their appointment.

Health attorneys can also be appointed under an Enduring Power of Attorney. The Enduring Power of Attorney is a legal document that enables a person to formally appoint another person/s to make financial, personal and/or health decisions on their behalf. However, the health attorney nominated in Enduring Power of Attorney can only exercise decision-making on behalf of the person (usually called ‘the principal’) should they lose capacity for decision making about health care matters. The health attorney must have accepted their appointment by signing the enduring document. The health care team is entitled to ask the health attorney to provide proof of their appointment.

Another type of substitute decision-maker is ‘statutory health attorney’. Informally appointed under the Powers of Attorney Act 1998,³⁴ this person (or sometimes persons) is generally someone with a close and enduring relationship to the patient, on whose behalf it is appropriate for them to make decisions. A person claiming to be appointed as the patient’s statutory health attorney can give consent to withhold or withdraw treatment.

An adult’s statutory health attorney is the first of the following people who is readily available and culturally appropriate:

1. A spouse of the adult if the relationship between the adult and the spouse is close and continuing.

2. A person who is 18 years or more, who has the care of the adult and is not their paid carer. (A person receiving a carer’s pension or similar government benefit is not considered a paid carer under the legislation).

3. A person who is 18 years or more and who is a close friend or relation of the adult and is not a paid carer.

If no one is readily available and culturally appropriate to act as attorney the Adult Guardian becomes the patient’s statutory health attorney.

---

³² S. 76 Guardianship and Administration Act 2000 requires the medical officer to give the (health) attorney all the information necessary for them to make an informed exercise of their powers given under the Health Care Principle.
³³ Proof to the satisfaction of the medical officer in charge of the patient’s treatment
³⁴ Powers of Attorney Act 1998, s. 63 and s. 63
3.3.1 Consistency with good medical practice

Consent to the withholding or withdrawal of life-sustaining measures cannot operate unless the treating medical officer reasonably considers the commencement or continuation of the measure/s for the adult would be inconsistent with good medical practice. In other words, consent from a substitute decision-maker/s to withdraw or withhold treatment can only apply where the medical officer considers that providing that treatment would be medically futile. Or put another way, where the medical officer does not believe providing life-sustaining measures would be consistent with good medical practice, the substitute decision-maker's consent will be effective to withhold those measures.

Appendix 2 contains an excerpt of the speech by the Hon. R.J. Welford which amended earlier provisions in this area of the law. This provides further legislative context to decision-making and the general responsibilities of all those involved in acting in the best interests of the patient.

3.3.2 Effect of ‘objections’

The Guardianship and Administration Act 2000 provides that, in certain circumstances, a medical officer may not exercise their power to provide or not provide medical treatment if they know, or ought reasonably to know, that the person objects to the health care (‘Health care’ in this context can mean either the provision of life-sustaining measures or the withholding or withdrawing of life-sustaining measures).

Section 67 of the Act states:

Effect of adult's objection to health care
(1) Generally, the exercise of power for a health matter or special health matter is ineffective to give consent to health care of an adult if the health provider knows, or ought reasonably to know, the adult objects to the health care.
(2) However, the exercise of power for a health matter or special health matter is effective to give consent to the health care despite an objection by the adult to the health care if —
(a) the adult has minimal or no understanding of one of the following —
   (i) what the health care involves;
   (ii) why the health care is required; and
(b) the health care is likely to cause the adult —
   (i) no distress; or
   (ii) temporary distress that is outweighed by the benefit to the adult of the proposed health care.
(3) Subsection (2) does not apply to the following health care—
   (a) removal of tissue for donation;
   (b) participation in special medical research or experimental health care or approved clinical research.

In order for a substituted decision-maker’s consent to override a person's objection to health care (which could be either an objection to the withholding or withdrawal of a life-sustaining measure or the provision of a life-sustaining measure), the test in Section 67(2) must be satisfied. That is, a medical officer must assess the extent of the patient's understanding of the treatment involved and that temporary or no distress will be experienced by the patient.

The term ‘objection’ is defined to mean that the person indicates that he or she does not wish to have the health care, or that the adult previously indicated that he or she did not wish to have the health care if these circumstances arose, and since then he or she has not indicated otherwise. The legislation provides examples of how that objection may be indicated.

35 S. 66A(2) Guardianship and Administration Act 2000
36 Guardianship and Administration Act 2000 Schedule 4 definition of ‘object by an adult to health care’
An indication may be given in an enduring power of attorney or advance health directive or in another way, including, for example, orally or by conduct.

However, in practical terms, Section 67 deals with the effect of an objection that is made other than in an Advance Health Directive. As explained previously, if a person has made an Advance Health Directive that contains a relevant direction about the withholding or withdrawal of a life-sustaining measure, the matter may only be dealt with under that direction. In those circumstances, there is no scope for the adult’s substitute decision-maker/s to exercise the same powers under the legislation and object on behalf of the person making the directive. As a result, Section 67 does not apply to an objection made in an Advance Health Directive.
Consent - Summary Points

General

1. Life-sustaining medical treatment can only be withheld or withdrawn where consent is obtained or where legal authority is given to make the decision without consent.
2. Where the patient lacks capacity to make health care decisions, except in some acute emergency situations, consent is required before any life-sustaining treatment can be withheld or withdrawn.
3. Consent must be obtained through the following (in order):
   - the patient’s valid Advance Health Directive
   - a guardian appointed by the Queensland Civil and Administrative Tribunal
   - a health attorney under an Advance Health Directive or Enduring Power of Attorney
   - a statutory health attorney/s
   - the Adult Guardian.

Advance Health Directive

4. An Advance Health Directive is a formal document in which an adult provides direction about current and future health matters and may be used to nominate one or more people to make decisions on their behalf should they lose capacity to do so. An Advance Health Directive can be acted on only when the person loses capacity. If they regain capacity, the Advance Health Directive cannot be acted on.
5. The health care team is entitled to check the validity of an Advance Health Directive (see Section 3.1.2) and to sight the original or a certified copy of it.
6. Valid Advance Health Directives take legal precedence over treatment requests made by family members of the patient.
7. If a medical officer chooses not to follow a patient’s Advance Health Directive (see Section 3.1.2 for reasons for this), they must seek a second opinion from a senior medical officer or consultant, and must clearly and meticulously document the circumstances and decision-making process.

Substitute Decision-Makers

8. If there is no Advance Health Directive in place and there is not an acute emergency, consent is required from a patient’s substitute decision-maker/s before any life-sustaining measure can be withheld or withdrawn. The medical officer responsible for the patient’s care must make all reasonable efforts to contact the substitute decision-maker/s if the patient loses capacity, and the substitute decision-maker/s must exercise power in accordance with their appointment (see Section 3.2) and the Health Care Principle (see Glossary).

Objections

9. Even outside of Advance Health Directives, there is scope for a patient to object to the provision or withholding of life-sustaining measures, and scope to override that objection in particular circumstances (see Section 3.3.2).
4.0 DECISION-MAKING FRAMEWORK

4.1 A collaborative approach

Families and health care professionals have an obligation to work together to make compassionate decisions for patients who lack decision-making capacity, taking account of formal decisions or previously expressed patient wishes where they are known. Since the introduction of the Guardianship and Administration Act in 2000, end-of-life decision-making formalises a more collaborative approach, involving the patient’s family and/or friends and members of the health care team.

It is important to commit to a collaborative decision-making process involving the patient, their family and/or friends, and the members of the health team. The importance of a cohesive team in providing quality health care is widely recognised and is particularly important when making decisions about whether to withhold or withdraw life-sustaining medical treatment. Seeking agreement within the team about the most appropriate course of action can help to reduce the possibility of subjectivity or bias in cases of uncertainty.

It is also important to make it clear to patients and family members that diagnosis and prognosis are based on probability and past evidence rather than absolute certainty. Although death is a certainty for everyone, many aspects of medicine still remain an imprecise science. Regardless of the prognosis or disease trajectory, a collaborative approach can assist in achieving better outcomes for the most vulnerable patients.

In most situations where a patient is dying, the patient, family and health care team readily come to an agreement on appropriate medical management. However, disagreements can arise regarding treatment limitation decisions, or other aspects of end-of-life care. Most of these disagreements can be prevented by early, sensitive and proactive communication that clarifies goals of treatment, possible outcomes and the patient’s values and wishes.

In the event that a disagreement cannot be resolved, medical officers must seek a second opinion from a more experienced medical officer, or refer the matter to the hospital administration or ethics committee.

4.2 Discussion with families

While modern health care has the capacity to prolong life, it cannot do so indefinitely. Therefore, a realistic but compassionate discussion about prognosis, which includes the inevitability of death, is almost always in the best interests of the patient and those closest to them. This should be communicated in an honest and compassionate manner.

It is recommended that the medical officer initiate advance care planning discussions with the patient soon after a life-threatening illness or condition is diagnosed (see Part 2 – Ethical and Special Considerations for further detail). While this may not be possible at the time of diagnosis for a variety of reasons, the discussion about the patient’s available options for end of life care should occur as soon as appropriate. Elements of advance care planning may have already been raised in the context of available treatments, therefore discussing resuscitation planning may be acceptable to the patient and the family as a necessary extension of this discussion.

One of the most important goals of the decision-making process is effective communication, to ensure that patients have access to the necessary information and support to make informed decisions. Multiple studies have demonstrated that treatment at or near the end of life is rarely optimal. Unwanted life-sustaining treatments, sometimes described as ‘death-prolonging treatments’, are frequently provided and open communication about death and dying is often lacking. Early communication about goals, prognosis and options can improve patient care at or near the end of life by respecting and protecting patients’ choices and facilitating pathways toward palliative care.
Sometimes a patient may not wish some family members to be involved in discussions. It is always best to check with the patient and obtain their consent before discussing the patient’s condition with their family and/or friends.

Within this context the following diagram provides a broad outline of the decision-making process for a patient approaching the end of life:

**Decision-making process**

The medical officer, and/or other health professionals as appropriate, makes a full clinical assessment of the patient including options for care and uncertainties for future treatment.

As soon as practicable, discussions are held between the treating medical officer and the patient, and those closest to them to ensure all have as clear an understanding as possible of the patient’s condition, prognosis, their options for care and any uncertainties for treatment. This provides an early indicator for managing future expectations of the patient and their family, particularly if the patient will be cared for in the family home. Completing an ARP would be appropriate in this step.

Discussions are held with the patient and those closest to them about their life goals and goals for health care, such as their values that define quality of life and wishes for symptom control and pain relief. By this stage, patients and those closest to them should have been provided with information about the patient’s condition and other support available to them.

A clear understanding is developed between all parties of the clinical choices available, how these might match the goals of future health care, and when these goals might be reviewed.

Based on these discussions, the medical officer in charge of the patient’s care prepares a treatment plan to provide a formal record of the longer term clinical goals and the course of active treatment and supportive care that will be undertaken. The plan may be amended at any time in response to changing circumstances.

Following on from this, a five-step approach to communicating with dying patients and/or their family members about end of life decisions is provided in the next diagram. This approach addresses the issues that are most crucial and likely to arise, and recognises that life-sustaining treatments include palliative care.
Five-step process for communicating end-of-life decisions

**Step 1: Assess**
- assess patient’s condition
- discuss patient’s condition with them, including characteristics of disease and likely prognosis
- obtain consent to treat
- ask the patient to nominate their substitute decision-maker/s
- encourage the patient to complete an Advance Health Directive
- initiate Priority Care Plan (under development)

**Step 2: Treatment Goals**
- define goals of treatment
- try to establish a clear and realistic understanding of active treatment goals with the patient and their family
- describe the possibility or probability of treatment failure
- describe future palliative requirements to ensure patient comfort and dignity is maintained at all times
- initiate Acute Resuscitation Plan

**Step 3: Re-evaluate**
- provide emotional support and reflective listening
- refrain from making hasty decisions at this time
- re-evaluate the likelihood of treatment failure as necessary and communicate this to the patient
- take steps to ensure good relationship maintained with those closest to the patient
- obtain other medical/psychological/surgical etc opinions as necessary

**Step 4: Transition**
- as the patient’s condition and prognosis worsens, with the patient’s consent, involve those closest to the patient in discussions
- if disputes arise about treatment options, seek advice of senior medical officer with expertise in the area
- involve palliative care team to ensure transition from active treatment to comfort care

**Step 5: Palliative Support**
- discuss with the patient the possibility of withholding and/or withdrawing active treatments in the context of good palliative care
- if the patient loses capacity, make all efforts to locate their substitute decision-maker/s
- If steps 1-4 are followed, when patient loses capacity, there should be clear understanding of patient wishes

Some family members may feel as if they are ‘actively killing’ their loved one by withdrawing medical treatment rather than allowing the natural disease process to run its course, and will commonly experience feelings of guilt, anxiety and bereavement. It is important that they receive appropriate care and counselling, before and after the decision has been made to withdraw medical treatment. In particular, those closest to the patient should be advised that hospital social workers or counsellors are available to help the family through this difficult time.

Patients may also feel under pressure not to ‘abandon’ the family or ‘give up’ on life, even though their condition is in its terminal phase. Similarly, some patients may feel like a burden to family, friends and the health care system and wish to withdraw treatment prematurely. Again, communicating openly and honestly with the patient, family and staff is the most effective way to achieve understanding, and to alleviate the ‘guilt’ associated with dying and/or withdrawing treatment.

### 4.2.1 Patients with capacity

Where a patient has capacity, their directions for health care must be followed, including withholding and/or withdrawing medical treatment according to their instructions. Where the patient has capacity to make health care decisions and is likely to require life-sustaining treatment, consent procedures should be put in place to ensure their views and decisions are respected when they lose capacity. This may include any combination of the following:

- the medical officer conducting advance care planning discussions with the patient, including initiating a Priority Care Plan (currently under development)
- the medical officer formulating an Acute Resuscitation Plan after discussions with the patient
- the patient appointing a health attorney who represents their interests if they lose capacity
- any member of the health care team encouraging the patient to formalise their end-of-life wishes by completing an Advance Health Directive.

Discussion about diagnosis, prognosis and preferences for care should be encouraged, but not forced.
A patient’s wish not to discuss specific treatments or interventions, or the possibility of his or her own death, should always be respected and emotional support provided. In situations where the patient does not want to discuss or decide on resuscitation, the medical officer should sensitively establish whether the patient would prefer to have others outside the health care team involved in the decision-making process. This may include religious or spiritual advisors, as discussed with the patient, and where the patient does not have capacity, under the advice of the patient’s substitute decision-maker.

Where the patient is willing to talk about treatment options, the discussion should include information about the risks, benefits, side-effects, likelihood of success and anticipated level of improvement if treatment is given, the likely outcome if treatment is withheld, and any other alternatives that might be considered.

Patients’ preferences for life-sustaining treatment are not static over time and should be regularly reviewed by the medical officer responsible for the patient’s care, particularly as the patient’s condition deteriorates.

In cases where a patient requests non-standard forms of treatment that, in the considered opinion of the medical officer in charge, would not benefit them and would be against their best interests, the medical officer must discuss the implication of these requests with the patient in an open, frank and honest manner. If, after these discussions, the patient still insists on treatment that would, in the medical officer’s opinion, be inconsistent with good medical practice and offer no benefit to the patient, the medical officer must refer the patient to, or obtain advice from, another medical officer/consultant experienced in that area of medicine as soon as practicable.

If there is any suggestion that the patient is being coerced into requesting treatment that in the considered opinion of the medical officer and other members of the health care team is not in their best interests and may cause harm, they should refer the matter to a senior medical officer or take the case to the hospital’s administration or ethics committee. It should be remembered that in these circumstances the Office of the Adult Guardian should be contacted for advice as soon as practicable.

### 4.2.2 Patients without capacity

Legal, ethical and clinical decision-making becomes increasingly complex and challenging where a patient who lacks capacity has not clearly expressed their wishes to family or those closest to them. In this case, medical officers and other members of the health care team, as appropriate, must discuss end-of-life issues as early as possible with the patient’s substitute decision-maker/s, which in most instances is a close family member.

Sometimes a patient who lacks capacity may have expressed a prior wish that some family members not be involved in discussions about their health care. These wishes must be followed when the patient loses capacity, particularly if formally directed in an Advance Health Directive.

It is always necessary to follow Queensland Health’s standards for confidentiality before discussing a patient’s condition with their family or friends.

All discussions should be conducted in an appropriate, comfortable and preferably private setting. If the medical officer is unfamiliar with members of the family, where practical, time should be spent identifying each family member’s relationship to the patient. This provides an opportunity to observe family members interacting with the patient and with each other before approaching those with the statutory decision-making ability.

All requests for continuing treatment should be given careful consideration before making decisions about the appropriateness of treatments. Any request for active treatments should lead to a review of the diagnosis and prognosis and the margins of certainty in each aspect. At the appropriate time, the medical officer responsible for the patient’s care should explain clearly (if possible in non-technical terms) to the patient and their family why they think the desired trial or treatment is inappropriate.
The question ‘Do you want everything done for [name]?’ should be avoided. No person could, without enormous guilt, answer in the negative on behalf of a loved one. Instead, reframe the discussion to address the patient’s comfort levels in the context of their prognosis and likelihood of recovery.

Discussions about tube-feeding in particular can be charged with guilt that failing to provide artificial hydration and/or nutrition represents denying the patient fluids and starving them to death. The advice of a senior medical officer/consultant should be obtained in decisions to withhold or withdraw artificial hydration and/or nutrition.

Discussion of appropriate treatment options with the patient’s substitute decision-maker/s should include information about the risks, benefits, side-effects, likelihood of success and anticipated level of improvement if treatment is given, the likely outcome if treatment is withheld and any other alternatives that might be considered.

Within this context, medical officers are under no obligation to offer treatments that would provide no benefit to the patient, that is, treatment that would be considered potentially futile. Substitute decision-makers have responsibilities under the legislation and are required to act in accordance with the General Principles and the Health Care Principle (see Glossary). Where substitute decision-makers are considered not to be complying with either of these, the Adult Guardian should be contacted.37

4.3 Disclosure and informed consent

In non-urgent situations, the legislation requires that consent is obtained in order to withhold medical treatments.38 This applies to both patients with capacity and patients who lack capacity. For patients without capacity, it is presumed that in non-acute emergency situations, sufficient time is available to find the patient’s substitute decision-maker/s and discuss the patient’s end-of-life wishes, or to obtain the patient’s Advance Health Directive, if they have one.

However, the reading of this provision is the cause of some uncertainty and also linked to the requirement for informed consent (see Section 4.3.1). The most extreme interpretation of these provisions would have medical officers offering every conceivable medical treatment in order to obtain consent to withhold it (that is, not to provide it). This has caused implications for the practical application of the legislation that are unlikely to have been intended by Parliament when the withholding or withdrawing life-sustaining measures provisions were introduced in 2001 (see Appendix 2).

Discussing treatment options that in all reasonableness cannot be provided or would be considered potentially futile is counter-productive to an effective medical officer/patient relationship. Falsely raising hopes for a dying person and their family by suggesting forms of treatment that would not benefit the patient and have the potential of causing harm is cruel, inhumane and would not constitute good medical practice.

Disclosure of all possible treatments, including ‘extraordinary’ measures, may not necessarily benefit the patient and could potentially lead to confusion and unrealistic expectations of recovery. The medical officer responsible for the patient’s care must use his or her best judgement in applying the standards of good medical practice and proceed with a course of action that provides the maximum benefit to the patient, taking all factors into consideration including balancing the available resources and care needs of other patients (see Part 2 – Ethical and Special Considerations).

37 S. 43 Guardianship and Administration Act 2000
38 S. 63A Guardianship and Administration Act 2000
Therefore, it is Queensland Health’s policy that the medical officer responsible for the patient’s care is under no obligation to disclose or offer all possible treatments that cannot be offered in order to gain consent to withhold them: that is, treatments which, for reasons of good medical practice would be futile, potentially harmful, and offer no benefit to a dying patient.

However, it is recognised that prospective decision-making in the end-of-life arena is fraught with uncertainty. These are not single-dimension, linear decisions. Every patient’s condition has subtle and not so subtle differences and a patient’s disease trajectory and treatment decisions will reflect these differences. Therefore, decisions about what treatments to offer dying patients must be made based on the specific needs of each patient, not on what treatment was offered to another patient of similar age or condition.

### 4.3.1 Informed consent

The foundation for decision-making about withholding and withdrawing life-sustaining measures can shift depending on whether or not consent by the patient or their guardian/carer is valid. The concept of informed consent has been greatly influenced by medical case law and ethical debate in this area.

In brief, informed consent concerns the medical information patients need to know so they can make decisions, sometimes in advance, about health matters.

Decision-making responsibility is also a key feature of discussions about informed consent. Queensland Health’s policy statement about informed consent for invasive procedures states:

‘The responsibility for ensuring a patient has the necessary information and advice lies with the medical practitioner who performs a procedure, operation or treatment. In the event that the treating Medical Practitioner asks another Medical Practitioner (delegate) to obtain consent on their behalf, the treating Medical Practitioner remains legally responsible for ensuring that the Medical Practitioner obtaining consent fully understands and discloses the elements of consent to the patient/parent/guardian (if a child)/substitute decision-maker.

The Medical Practitioner (or delegate) obtains consent from the patient/parent/guardian/substitute decision-maker according to the protocols which guide an effective communication process, i.e.

- the procedure outlined in this policy, including the use of procedure-specific consent forms

There is contention about what constitutes informed consent for refusal of medical treatment. The National Health and Medical Research Council (NHMRC) National Statement describes consent in terms of it being voluntary and based on sufficient information and adequate understanding. In summary, the NHMRC advises that informed consent:

- requires information to be presented in ways suitable to the person making the decision to facilitate an understanding of both the proposed procedure or treatment and the implications of undergoing it
- may be expressed orally, in writing or by some other means, depending on the nature, complexity and level of risk of the procedure or treatment and the person’s personal and cultural context, and
- requires there be no coercion or pressure, recognising that coercion may not be overt, but might reflect deference to the health professional’s perceived position of power, or to someone else’s preferences.

---

39 S. 63A Guardianship and Administration Act 2000

40 This description of consent is adapted from Chapters 2.2 and 2.3 of the NHMRC’s National Statement on Ethical Conduct in Human Research 2007
While the National Statement from the NHMRC is specifically designed for consent to research, it embodies the common law principles of consent and refusal of medical interventions and is relevant to these guidelines.

The intent behind the concept of informed consent is to protect both parties. A patient needs to know what options are available, what the expected outcomes are for each option, and what the success rates and incidence of side-effects are for each option. The treating medical staff need to know that the patient understands the implications of their decision.

A range of specific consent forms used in Queensland hospitals form part of general pre-admission procedures. These forms are co-signed by both the patient or their guardian/carer and the treating doctor. Once the form is signed, it is taken that the patient has been informed (directly or through a guardian/carer) and consent given.

However the ethical principles concerning informed consent turn on what is considered ‘appropriate’ disclosure of information from the doctor and ‘adequate’ comprehension by the patient. For consent to be valid, it must also be voluntary (free of any coercion) and given by a person assessed to be competent and informed as to the risks involved. Again ethical questions arise about the subjective nature of many of these elements, for example, appropriateness and adequacy of the information, and the level of patient capacity. There are four elements of informed consent generally identified in the literature:  

1. competence and capacity  
2. voluntariness  
3. disclosure of information  
4. understanding and acceptance of information.

To add to the complexity of issues in applying informed consent principles in this area, some consent can be verbal or implied, and consent need not be in writing to be enforceable.

The Queensland Health Policy Statement – Informed Consent for Invasive Procedures provides details and links to the range of consent forms and other related practitioner and health consumer resources on the Queensland Health website.

It must be pointed out that there are clinical, ethical and legal differences between consent to provide medical treatment and consent to withhold or withdraw medical treatment. Consent to provide medical treatment (such as for a surgical procedure) operates on a more positive premise – that once the patient receives the treatment they will recover to an acceptable level. Consent for withholding and withdrawing medical treatment comes from a different position along the clinical decision-making continuum, recognised as ‘end of life’. Communication between the health care team and the patient and their family is paramount in these circumstances. Discussing and documenting the decision-making pathway is required by law, even if there is limited resolution of conflict situations. How some of these matters are resolved involves ethical considerations as much as clinical considerations, and the situation may not not remain static for many patients. For these reasons, it is not necessary for the patient and/or their family to sign the Acute Resuscitation Plan form; documentation of how consent has been discussed and/or arrived at is sufficient to meet the requirements of the law. Part 2 of these guidelines covers a range of ethical considerations in decision-making in this area (see Appendix 1 for the table of contents).

---

42 Exceptions to this are under the Human Tissue Act 1983
4.4 Disputes

Disagreements between the patient and his or her family may arise if the family is not properly informed by the health care team about the directions given by the patient. Guided by the patient’s best interests, every effort should be made to communicate this information to the family (see Section 4.2 for more information). All requests for continuing treatment should be given careful consideration before decisions about the appropriateness of treatments are made (see Part 2 – Section 4 for a discussion about potentially futile medical treatment).

Disputes can also arise when the patient and/or their family disagree with the health care team on medical treatment proposed, the prognosis of the patient’s condition, and whether or not the medical treatment is in the best interests of the patient.

Families of patients without decision-making capacity who demand continued treatment might have unrealistic expectations about what can be achieved, particularly when the treatment is not considered standard for that condition or when its application would be completely ineffective and would not benefit the patient. More often, a family will ask for ‘everything to be done’ if they are not ready to accept the patient’s inevitable death. This situation may be exacerbated when the family is not engaged early in treatment planning before the onset of the dying process, or where guilt may be associated with fractured or distant relationships within the family.

The efforts of the health care team, other health professionals, pastoral care workers, social workers or other counsellors should be directed to supporting family members and helping them to resolve their difficulties in accepting the reality of the patient’s impending death. In such circumstances, it is preferable to continue treatment until conflict with relatives is resolved, however, time-critical situations pose extremely difficult choices and challenges. Senior medical officers/consultants should be involved in all these discussions.

Also, there may be more than one eligible decision-maker for the decision to withhold or withdraw life-sustaining measures. Negotiation is more difficult where there is disagreement between legally appointed substitute decision-makers, such as multiple guardians or statutory health attorneys. Potential disagreement can usually be overcome through sensitive and considered communication between interested parties by focusing upon the known wishes of the patient and their best interests. If the patient has formally documented their wishes in an Advance Health Directive before loss of decision-making capacity then, legally, these wishes prevail over the demands of the family.

In the case of dispute or disagreement, health professionals must be able to demonstrate a reasonable justification for their decisions, particularly those which deviate from established clinical guidance. Detailed clinical notes should be kept of any guidelines consulted or additional opinions sought.

4.5 Resolving disputes

Not all dispute resolution options will be available in all clinical contexts. However, the simple approaches should be taken first in the context of providing the best possible care for the patient and compassion for the family. These include the following:

- **Allow time**
  
  Unless decisions about life-sustaining medical treatment need to be made urgently, allowing families time to come to terms with the impending death of their loved one, and to seek further discussion with family or others providing support, may be sufficient to resolve most issues.

- **Seek a second opinion**
  
  A request for a second medical opinion may be raised with, or directed to, any member of the health care team at any time. Offering a second opinion in the early stages may also be appropriate if the family are displaying anxieties or uncertainties regarding
diagnosis or prognosis. It is the responsibility of the medical officer in charge of the patient’s care to arrange any second clinical opinion/s and arrange counselling for the family, as appropriate.

- **Consider a time-limited treatment trial**
  Where it is in the best interests of the patient, consideration may also be given to a time-limited treatment trial. This may be undertaken to provide more time for the family to come to terms with the decisions required, but may also help to clarify prognostic uncertainty or resolve disagreement about prognosis.

- **Seek assistance with communication and resolution**
  Sometimes difficulties with communication and a family’s inability to reach final acceptance may mean resolution is not possible within the limitations of the health care team who are required to balance the care needs of many other patients. In these difficult cases, consideration should be given to involving a third, independent person who is sufficiently experienced in these matters. This person may be a senior member of the hospital administration, a senior health professional, or another independent person agreed upon by those involved and who has sufficient seniority and experience to be respected by all parties.

If the above steps are clearly not working and the situation becomes intractable, the patient and their family should be given the option of transferring the care of the patient to another facility. These decisions must be made through the appropriate channels of the hospital’s administration and/or ethics committee.

If consensus cannot be reached about a decision or if the substitute decision-maker/s refuses to comply with the Health Care Principle (see Glossary), the Adult Guardian should be consulted to resolve any dispute. However, the Adult Guardian can be referred to only when the patient does not have capacity. Clear documentation of the decision-making process which led to the circumstances, including notes of discussions with family members, will be required in these cases.

### 4.6 Decision-making process

The decision not to provide life-sustaining medical treatment is a complex, emotionally-charged and confronting issue for the patient, medical team and family alike. When a patient has the capacity to make decisions for themselves, the treating medical team must respect the patient’s wishes. Doctors and medical staff have a duty to respect the patient’s right to refuse unwanted treatment and health care. This right is based on the well-founded principle of autonomy. Not respecting a patient’s right to refuse unwanted medical treatment is considered assault. Treatment given to a patient without obtaining their consent can give rise to an action in battery (civil assault). It can also give rise to an action for criminal battery (assault) or if a procedure is administered, it may give rise to an action of ‘doing bodily harm’ or ‘doing grievous bodily harm’.

When the patient lacks capacity, then the decision to withdraw medical treatment is ultimately a medical decision made in the best interests of the patient. Medical officers need to be careful not to transpose their beliefs, values and priorities on to the patient, but rather make a concerted effort to ascertain those of the patient. Determining what will be in the patient’s best interests requires consideration of medical and ethical factors.

When determining what course of action is in the patient’s best interests, the treating medical team should conduct a formal medical review of the patient’s condition and prognosis. Discussion with family members is particularly important when the patient does not have the capacity to make or communicate decisions, as the family is likely to be aware of previously expressed views the patient may have held regarding end-of-life wishes, or to have an intimate
knowledge and understanding of the patient’s wants, values and beliefs (see Ethical and Special Considerations in Decision-Making for Withholding and Withdrawing Life-Sustaining Measures from Adult Patients). Areas of patient care frequently discussed in a formal medical review include prognosis of the patient’s condition, the efficacy of current treatment, whether it is justified, and any alternative treatments that may offer a benefit to the patient, including palliation options.

Consideration should also be given to:

- the likelihood of meaningful recovery
- the patient’s length of treatment
- the degree of reported or perceived patient suffering
- whether treatment has achieved its goals
- whether the patient’s condition has improved, deteriorated or stayed the same
- the nature of treatment required
- the patient’s wishes if known
- the views of family members.

Families and carers usually want to feel involved in elements of patient care. They will also want to feel ‘part of the team’ in making end-of-life decisions about the patient. Keeping in mind patient confidentiality obligations, it is important that information such as the patient’s progress, treatment options and staff opinions be discussed with the family as early as possible in an open, honest and compassionate way (see Section 4.2). The treating medical team should aim to reach a consensus with those close to the patient on what treatment would be in the best interests of the patient, particularly where decisions are required about life-sustaining measures.

Holding regular family meetings is an effective way to explore these emotive and sensitive issues, and to gain greater understanding of the patient’s wants regarding life-sustaining medical treatment, their values and beliefs. These meetings will also educate the family and help them come to terms with their loved one’s prognosis. The meetings should commence as early as practicable to avoid crisis-driven decisions when the patient’s condition declines.

### 4.6.1 Who is involved in decision-making?

Patients with capacity may encounter several different health professionals when planning end-of-life care. The health care team may include medical specialists, surgeons, general practitioners, nurses and allied health workers (such as social workers), patient advocates, chaplains or pastoral care workers in end-of-life care/planning discussions, either directly or in supportive roles.

Individual members of the treating team (such as nursing and allied health staff) may have closer or prolonged involvement with the patient and may be aware of the patient’s values and wishes. Other team members may be more involved in how the patient is psychologically or spiritually coping with illness. Each member may bring valuable perspectives and information to the process of planning care and their collaborative involvement should be actively pursued.

All treatment decisions for acutely ill patients at the end of life who have capacity should be made in the context of good quality palliative care. In some cases, however, patients may not wish to discuss future medical treatment options, including resuscitation planning, and they should not be forced to do so. In these situations, the medical officer should sensitively establish whether the patient would prefer to have others make decisions on their behalf, such as a senior medical officer, possibly with the advice of the family and/or those closest to them.

In circumstances where one team member disagrees with the others, the team as a whole should consider the basis for disagreement and seek the opinions of experts from the same
discipline as the disagreeing member. In the event that support for this position cannot be found, it may be appropriate for the dissenting member to withdraw from the treating team.

As in other areas of clinical practice, a health professional may exercise conscientious objection and not participate in a particular practice which is contrary to his or her moral beliefs. Counselling or other psychological support may be appropriate where disagreement occurs about the appropriateness of treatment limitation, particularly for nurses who, in some settings and by their more intimate involvement in the care of dying patients, may be more acutely aware of distress experienced by the patient and those closest to them.

4.6.2 Decision-making Flowchart

The following flowchart has been devised to guide the consent process for withholding and withdrawing life-sustaining measures for patients without capacity. While the flowchart guides decision-making, it is indicative only, as decision-making in the end-of-life area is characterised by an almost infinite number of variables.

This flowchart broadly depicts the consent process for decision-making about withholding and withdrawing life-sustaining measures. The steps in the ‘Assess, Discuss, Plan’ box are where the doctor in charge of the patient’s treatment makes a clinical assessment of the patient’s condition. The available options for treatment are discussed with the patient and, with their consent, those closest to the patient. Following these discussions, a treatment plan is made, which may include completing a Priority Care Plan (under development) and/or an Acute Resuscitation Plan. Consent requirements in the circumstances outlined (acute emergencies and non-acute emergencies) are listed in the box to the right.

The law states that if providing life-sustaining measures would be inconsistent with good medical practice, the measures may be withheld or withdrawn without consent, but only in
acute emergency situations. Consent must be obtained where the medical officer responsible for the patient’s care knows that the patient objects to withholding or withdrawing life-sustaining measures.

**Acute and non-acute situations are characterised by the time required to make a decision to withhold or withdraw life-sustaining measures.** If the decision is required immediately to maintain the patient’s life and health, then it qualifies as an acute emergency.

In non-acute emergency situations, doctors may not act unilaterally to withhold or withdraw any life-sustaining measures. In these circumstances consent must be obtained from the list of available substitute decision-makers in the order as indicated in the diagram.

It should be acknowledged that the wording in the purple box ‘clinical decision is made to withhold or withdraw life-sustaining measures’ contrasts with the wording used in the legislation – ‘the commencement or continuation of the measure for the adult would be inconsistent with good medical practice’. While there are subtle legal nuances in the difference in these terms, the intent is to more easily capture this concept in a flowchart. While both terms are a euphemism for decision-making around ‘futile treatment’, the consent process is the same. Futile treatment is discussed further in *Part 2 - Ethical and Special Considerations*. 
Decision-Making Framework - Summary Points

General
1. If the patient has formally documented their wishes in an Advance Health Directive before loss of decision-making capacity then, legally, these wishes prevail over those of the family.
2. Doctors and medical staff also have a duty to respect the patient’s right to refuse unwanted treatment and health care.

Collaborative approach
3. When a patient lacks capacity to make decisions about end of life care for themselves, the decision-making should be collaborative, including family members and the health care team.

Communicating with families
4. Early open, frank and honest communication with patients and families about goals, prognosis and options can improve patient care by identifying, respecting and protecting patients’ choices. It may also prevent disputes over treatment and care.
5. Family members who agree to withdrawing treatment may need support through feelings of guilt, anxiety and bereavement.

Disclosure and informed consent
6. In non-urgent situations, the legislation requires that consent is obtained to withhold medical treatments. The assumption is that there is sufficient time to discuss treatment options. This provision is also linked to the requirement for informed consent.
7. While there is some uncertainty over ‘informed consent’ with regard to withholding and withdrawing life-support measures, it would be cruel and inhumane to offer or disclose treatment options that cannot be provided or would be considered potentially futile. This would not constitute good medical practice.

Dispute Resolution
8. If open, honest and frank communication has not forestalled or resolved disagreements with families, these options include:
   - providing support (through other health professionals, pastoral care workers, social workers, other counsellors) to the family
   - allowing families time to come to terms with the impending death of their loved one
   - offering a second opinion
   - considering a time-limited treatment trial
   - involving an independent third party to help resolve any issues
   - giving patients and their family the option of transferring to another facility
   - consulting the Adult Guardian

Clear documentation will be required in these cases.
5.0 CLINICAL CONSIDERATIONS

Clinical decisions to withhold or withdraw life-sustaining measures seek to avoid unwanted, excessively burdensome or insufficiently beneficial interventions for patients at the end of life. Discussions about withholding life-sustaining measures should always be approached with sensitivity and with close attention to the clinical context and specific goals and desires of the individual for whom the measures are being considered.

5.1 Good medical practice

The practice of medicine is complex and multifaceted, but the key objective is to serve the best interests of the patient.

Medical officers are expected to base their practice of medicine on some fundamental principles including - integrity, truthfulness, fidelity, compassion, and confidentiality. Guidelines recently released by the Australian Medical Council on good medical practice also include the qualities of patient-centeredness, good communication and clinical judgement.

Professional judgments are made by medical officers about how they practice medicine and apply these qualities. Sometimes these judgements may conflict with a patient’s wishes for their end-of-life care. Good medical practice also requires adults’ wishes to be respected to the greatest practical extent. This may include respecting an adult’s right to die rather than receive medical treatment to which they have a profound religious objection (for example, see Blood transfusions in Section 5.6).

Good medical practice requires the medical officer responsible for the care of the patient to adhere to the accepted medical standards, practices and procedures of the medical profession in Australia. All treatment decisions, including those to withhold or withdraw life-sustaining treatment, must be based on reliable clinical evidence and evidence-based practice. All available information will be collected about the patient’s condition, diagnosis and prognosis, including the stability of the patient’s condition over a period of time and the underlying pathology.

Good medical practice also involves establishing a relationship with the patient and their substitute decision-maker/s to ensure the best interests of the patient are upheld in all decision-making. Therefore, in discussing the range of options available to a patient, medical officers are obliged to consider the patient as a unique individual. The medical officer in charge of the patient’s care should offer only treatments that are reasonably considered, in all the known circumstances, to be of potential benefit to that patient. Offering treatment that for clinical reasons would be potentially futile and could cause harm to the patient is considered cruel and inhumane and not conducive to a beneficial patient-clinician relationship.

Where doubt exists about the diagnosis or prognosis, advice should be sought from another senior clinician with experience of that condition before making decisions about withholding or withdrawing active medical treatment. This should also be the case when the health care team has limited experience of the condition, particularly with comparatively rare disorders, or there are disparate views about treatment. For example, where a patient is in a post-coma unresponsive state, advice will usually be sought from a clinician with expertise in the long-term consequences and management of brain injury.

Where the medical officer in charge of a patient’s care has reasonable doubts about a treatment’s potential benefit (or concerns the treatment could cause potential harm), treatment

---

43 S. 2 Legal Framework of this guideline reproduced the elements of good medical practice in end of life care from the Australian Medical Council. Australian Medical Council, Good Medical Practice: A Code of Conduct for Medical Officers in Australia, July 2009
should be given for a trial period with a subsequent pre-arranged review. If, following the review, it is decided the treatment has failed or ceased to be of benefit to the patient, its withdrawal may be considered. The appropriate consent pathway must be followed if there are any changes to prognostic information following expert opinion.

**Treatment should never be withheld merely on the grounds that it is easier to withhold treatment than to withdraw treatment which has been initiated.**

Wider consultation, including a second opinion from an experienced medical officer should be sought where there are doubts about a proposed decision. The method of obtaining second opinions should be governed by the standards of good medical practice and nature of the circumstances. For example, palliative care professionals should be involved in discussions with dying patients and their families, and a senior medical officer or consultant should determine the efficacy of the use of artificial hydration and nutrition for a dying patient and be involved in decisions to withhold or withdraw it.

A medical officer will be protected from criminal liability where they provide palliative care in good faith and with reasonable care and skill. The care must be reasonable having regard to the patient’s state at the time and the individual circumstances and must be documented by the medical officer in charge of the patient’s care. The protection does not permit euthanasia or assisted suicide.

### 5.2 Resuscitation planning

Resuscitation planning in these guidelines refers to advance discussions and decisions regarding actions to be taken for a patient in the event of a cardiac and/or respiratory arrest. In all instances this will involve consideration of CPR. However, other life-sustaining measures may also be appropriate, according to good medical practice.

Comfort care and palliative support must always be initiated if the decision is to withhold or withdraw active medical treatment.

Planning resuscitation for a patient depends on the extent to which death is regarded as an unavoidable and impending consequence of the patient’s underlying illness. The medical officer responsible for the care of the patient has an important role in helping the patient and those closest to them make appropriate plans for their future care in a sensitive but realistic manner, making clear if resuscitation methods could be successful. Helping patients to make a clear decision about their wishes about resuscitation should be regarded as a marker of good practice in any health care setting and the use of advance care planning (of which resuscitation planning is a part) should be subject to regular clinical audits.

Queensland Health has developed an Acute Resuscitation Plan form (ARP) to formalise the decision-making documentation process for resuscitation of patients considered ‘at risk’ of cardiac and/or respiratory arrest (see Section 2.6 Transparency and accountability).

#### 5.2.1 Who is suitable for an ARP?

Resuscitation planning is intended for those patients who are considered in all reasonable circumstances to be at risk of cardiac and/or respiratory arrest in the foreseeable future. Discussing resuscitation planning for patients who are not acutely ill, particularly when not initiated by the patient, is likely to be inappropriate, and could be misinterpreted. However, for some patients, often those with serious, chronic and ultimately fatal conditions, cardiac and/or respiratory arrest is an anticipated consequence of their illness. While this may be foreseen, the timing of an acute event is less predictable, and so resuscitation planning for appropriate response is desirable.

In anticipation of the patient’s deteriorating condition, discussions about end-of-life decision-making are best initiated as soon as practicable. This will identify any unmet needs and preferences and give a clear decision path for other members of the health care team in the case of an acute event.
While national and international research suggests that using prognostication to dictate the timing for advance care planning for acutely ill patients can be problematic, some indicators about when to initiate resuscitation planning may be helpful.

‘Prognostication is inherently difficult and inaccurate, even when informed by objective clinical indicators, and the trend is usually to over-estimate prognosis and to under-estimate planning for possible need, especially for those with non-cancer illnesses’.\(^{44}\)

Therefore sometimes it may be appropriate to lean towards instinctive, anticipatory and ‘insurance-type’ thinking, rather than pure prediction of acute events based on a disease trajectory. The initiation of advance care planning (see Section 8.1), the process by which better end of life care can be achieved for all patients, is an attempt to improve the capacity to predict. As stated earlier, resuscitation planning is part of the advance care planning process. The UK Gold Standards Framework\(^ {45}\) identifies three triggers to determine patients who should receive supportive/palliative care. Building on this framework can also help to identify patients who might be suitable for resuscitation planning. The following three triggers are adapted from the Gold Standards Framework:

1. **The surprise question:** ‘Would you be surprised if this patient were to die in the next six to twelve months?’ This is an intuitive question integrating co-morbidity, social and other factors. If the doctor responsible for the patient’s care would not be surprised, then resuscitation planning is likely to be appropriate. The importance of advance care planning for patients in the group considered to be most ‘at risk’ of an acute event can determine what measures might be taken to improve their quality of life now and in preparation for the dying stage and transition to palliative care. The surprise question can be applied to years/months/weeks/days and trigger the appropriate actions. The aim is to enable the right thing to happen at the right time. Some clinicians find it easier to ask themselves: ‘Would you be surprised if this patient were still alive in six to twelve months?’

2. **Choice/Need** – The patient with advanced chronic disease or acute illness makes a choice for comfort care only, not ‘curative’ treatment, or is in special need of supportive/palliative care. For these patients, their preference not to have CPR can be documented on the ARP.

3. **Clinical indicators** – General and specific indicators of advanced disease for each of the three main end-of-life patient groups - cancer, organ failure, and elderly frail/dementia are contained in the Gold Standards Framework Prognostic Indicator Guidance. An adapted version of this guidance appears in Appendix 3.

**5.2.2 Presumption in favour of resuscitation when there is no documented decision**

In emergency situations, where there is little time to make a proper assessment about the appropriateness of resuscitating the patient and no prior decision has been made or no consent to withholding obtained, the presumption will be in favour of life-sustaining medical treatment, which may include CPR. Treatment may be withheld or withdrawn at a later stage when more information is available about its appropriateness.

If no explicit decision has been made in advance about resuscitation and the express wishes of the patient are unknown and cannot be ascertained, and if uncertainty exists about diagnosis or prognosis, there should be a presumption that medical officers and other members of the health care team will make all reasonable efforts to attempt to revive the patient in the event of cardiac or respiratory arrest. In such emergencies, there will rarely be time to make a thorough assessment of the patient’s condition and the likely outcome of resuscitation efforts, and so attempting resuscitation will usually be appropriate.


Medical and nursing colleagues should support anyone attempting resuscitation in such circumstances. There may be some situations in which resuscitation efforts are commenced on this basis, but during attempted resuscitation, further information comes to light that makes continuing resuscitation efforts inappropriate. That information may consist of an ARP or a valid Advance Health Directive refusing, for example CPR in the current circumstances, or further clinical information showing the treatment will not be successful. In these circumstances, continued attempted resuscitation would be inappropriate.

For some patients, attempting resuscitation will be clearly inappropriate (for example, a patient in the final stages of a terminal illness where death is imminent and unavoidable and resuscitating the patient would not be successful), but for whom no formal decision about resuscitation has been made. In such circumstances, senior medical officers who make a considered decision not to commence resuscitating a patient should be supported by their colleagues, and the decision and its rationale/justification appropriately documented.

5.3 Cardiopulmonary resuscitation (CPR)

CPR is defined as a life-sustaining measure in both the Guardianship and Administration Act 2000 and the Powers of Attorney Act 1998. Medical officers have at their disposal a range of clinical procedures about how to perform CPR in a variety of contexts. The information in this section is not intended to replace that material, rather it offers considerations for decision-making about CPR for patients at the end of life in the context of advance care planning, particularly resuscitation planning.

CPR is performed to restore breathing (sometimes with support) and spontaneous circulation in a patient in cardiac and/or respiratory arrest. CPR is an invasive medical intervention and includes one or a combination of the following:

- chest compressions
- attempted defibrillation with electric shocks
- injection of powerful drugs
- ventilation of the lungs.

The probability of success for CPR depends upon several factors, including where the arrest occurs, the patient’s age, how soon after the arrest CPR is attempted, and the equipment and staff available to deliver it. The rate of survival after CPR in hospital to discharge ranges between 15 and 20 percent. Lower rates of survival (one to four percent) are reported in patients with pre-existing hypotension or renal failure, and negligible survival rates are reported for conditions, including septic shock, acute stroke, metastatic cancer and severe pneumonia.

In the immediate post-CPR period, the patient needs careful observation and most likely admission/transfer to an intensive care or coronary care unit. This is an emotionally-charged time for the patient’s family and friends, and at the same time the health care team will be faced with exceptionally difficult clinical decisions. For example, some patients will need other life-sustaining measures to stabilise their condition, such as artificial ventilation. They may also require a range of other interventions, such as renal dialysis or haemofiltration and circulatory support with inotropic drugs and/or an intra-aortic balloon pump. The patient may also incur other post-CPR conditions, including injuries associated with rib or sternal fractures, hepatic or splenic rupture or severe brain damage through lack of oxygen.

All of the preceding factors should be taken into consideration by the health care team as part of the decision-making process.

Where CPR has not been successful in restoring the patient’s cardiopulmonary function, some difficult decisions will be faced by the patient’s substitute decision-maker/s if the patient lacks capacity. For example, when a patient is in the final stages of an incurable illness and death is expected within a very short time, CPR is unlikely to be clinically successful. In fact, it may unnecessarily prolong the patient’s life to the extent they may suffer an inhumane and undignified death.

To avoid the family witnessing their loved one dying in a distressing manner, care should be taken not to expose those close to the patient to unsuccessful CPR attempts, particularly if the prognosis is that treatment is futile and will offer no benefit.

For many patients receiving end-of-life care in hospital or in the community, the likelihood of cardiac and/or respiratory arrest is small and it is unlikely for a clinical decision to be made in advance of such an event. In this situation, it is not necessary to initiate discussion about CPR with the patient, or with the patient’s family.

In cases where there is an identifiable risk of cardiac and/or respiratory arrest because of an underlying incurable condition (such as cancer), or the patient’s medical history (such as recent myocardial infarction or stroke), or current clinical condition (such as severe sepsis), resuscitation planning should be commenced.

Where a patient’s condition worsens, discussions about CPR should be held with the medical officer in charge, and/or records obtained through the patient’s general practitioner. In these cases, palliative care practitioners should be involved in discussions with the patient and/or the patient’s family, particularly where death is reasonably predictable. There should be a full clinical assessment of the chances of a successful outcome, documented on the ARP and/or in the progress notes. Ensuring that discussion takes place about CPR and a decision is made in advance where possible, is preferable to making decisions in a crisis when there may be insufficient time to gather and consider all the relevant information about the patient’s wishes and clinical condition. Completing an ARP can guide the discussions in this regard.

It is widely acknowledged that clinicians are often reluctant to raise and/or discuss difficult issues, such as planning for resuscitation, particularly where the outcome is uncertain. However, failure to discuss unfavourable prognostic information may leave patients and their families with poor appreciation of their prospects. This impairs the ability of patients and their families to make informed choices about treatment options including CPR when they may wish to do so.

While it is often difficult to predict with any certainty those situations where an arrest may occur, there are many situations where the likelihood of cardiac and/or respiratory arrest is sufficiently high as to warrant discussions about CPR. Some triggers (see above prognostication chart) for initiating a conversation about CPR in relation to the goals of care include:

- recurrent admission to hospital with severe chronic illness
- a diagnosis of metastatic cancer
- steady deterioration of a chronic respiratory, cardiac, liver or neurological illness
- other progressive advanced life-limiting illnesses, such as severe end stage dementia or frailty.

In such situations, it is best practice to initiate these conversations early in the illness, even where the trajectory of illness may be unclear. It is important to identify those patients at foreseeable risk of dying in the short term, and for whom questions about the use of CPR exist, so that decisions about CPR can occur in a timely manner to the degree possible in advance of an emergency situation.

Where CPR is successful in re-starting the patient’s heart and maintaining breathing for a sustained period, the benefits of prolonging life must be weighed against the potential burdens
to the patient. Prolonging life is not always beneficial.\textsuperscript{48} For example, unsuccessful CPR attempts can also result in a range of coma states, unmanageable pain, long-term dependence or other potentially debilitating and adverse effects for the patient. As distressing as this is for all concerned, the patient’s substitute decision-maker/s must be consulted on all decisions during this difficult time.

Also where the patient has (or regains) capacity their wishes for CPR must be respected and accurate information given to them about the likelihood and length of survival that might realistically be expected.

While it is generally held that medical officers are under no legal or ethical obligation to offer medical treatment that is ‘futile’, the determination that CPR is ‘futile’ or ‘inappropriate’ is not wholly objective and is influenced by the values and assumptions of the medical officer about the potential outcomes.\textsuperscript{49} If unilateral decisions about CPR are taken by medical officers, the subjective nature of such assessments should be acknowledged, and should be open to review. If attempting CPR is thought to be futile then this opinion must be justified and the reasons for it recorded in the patient’s medical records\textsuperscript{50} (for more information, see \textit{Futile treatment, in Ethical and Moral Considerations in Decision-making for Withholding and Withdrawing Life-Sustaining measures from Adult Patients}).


CPR – Summary Points

Discussions about CPR as a life-sustaining measure must also include any potential risks and side-effects. The medical officer in charge of the patient’s care has responsibility for all clinical decision-making in this regard. However since CPR is a life-sustaining measure under the guardianship legislation, all reasonable efforts should be taken to involve the patient and their substitute decision-maker/s in the decision-making process through a collaborative approach.

The following points highlight matters to consider in resuscitation planning.

1. Decisions about CPR must be made on the basis of an individual assessment of each patient’s case.

2. Before making treatment plans regarding CPR, all efforts must be made to contact those closest to the patient, and/or the patient’s statutory health attorney. If this is unsuccessful, the Office of the Adult Guardian should be contacted, as circumstances permit.

3. Advance care planning, including making decisions about CPR, is an important part of good clinical care for those at risk of cardiac/respiratory arrest. Resuscitation planning should be initiated in those patients considered at risk of cardiac/respiratory arrest.

4. It is not necessary to initiate discussion about CPR with a patient if there is no reason to believe that the patient is likely to suffer a cardiac/respiratory arrest.

5. Where no explicit decision has been made in advance, there should be an initial presumption in favour of CPR.

6. If CPR would not re-start the heart and breathing, it should not be attempted.

7. Where the expected benefit of attempted CPR may be outweighed by the burdens, the patient’s informed views are of paramount importance. This applies to both patients with capacity and patients without capacity.

8. If the patient lacks capacity, those close to the patient should be involved in discussions to explore the patient’s wishes, feelings, beliefs and values.

9. If a patient with capacity refuses CPR, or a patient lacking capacity has a valid and applicable Advance Health Directive refusing CPR, these wishes must be followed.

10. Where there is lack of agreement about the likelihood of success for administering CPR to a patient, a second opinion should be sought. If agreement still cannot be reached, a second opinion should be obtained from a more experienced or senior clinician, and transferring the patient to another health care team considered.

11. All decision-making about administering CPR must be carefully documented in the patient’s records by the health care team. Queensland Health’s ARP form, implemented in April 2010, provides a process for this to be documented.
5.4 Artificial hydration and/or artificial nutrition

Artificial hydration refers specifically to techniques for providing food or water because the patient is unable to swallow. It includes the use of a nasogastric tube, percutaneous endoscopic gastrostomy (PEG feeding) and total parenteral nutrition. The provision of nutrition and hydration by artificial means requires the use of medical and/or nursing skills to overcome an inability to swallow, in the same way that artificial provision of insulin is given to diabetic patients to overcome the body's own inability to produce that substance.

Withholding artificial nutrition and hydration is a controversial area. In part, this is because the benefits and burdens of either nutrition or hydration may not be well known and involve difficult assessments of the patient. For example, patients may increasingly lose interest in eating or drinking in the later stages of a progressive or chronic illness. Often this occurs at a time when other body systems begin to shut down and may be part of the natural dying process. Problems in making assessments can arise because some patients under-report their symptoms as they may no longer be lucid at this time. Complications also arise where there are different perceptions and expectations between medical officers, members of the health care team and those close to the patient, about the presence or severity of symptoms, and the type of medical interventions the patient would want (or not want). For example, there may be emotional difficulties in deciding not to provide what those closest to the patient see as basic nurture and care.

Concerns about decision-making around withholding or withdrawing artificial hydration and nutrition go beyond the clinical to the societal level. Some commentators see that it is potentially dangerous to allow some forms of life-sustaining measures (artificial hydration and nutrition) to be withheld or withdrawn because it may eventually result in society's tolerance of withholding and withdrawal of life-sustaining measures from vulnerable adults, even though the withholding or withdrawal may be inappropriate.

The controlling idea is that policies of not providing [medically administered nutrition and hydration] will lead to adverse consequences because society will lose its ability to limit decisions about [medically administered nutrition and hydration] to legitimate cases, especially under pressures of cost containment in health care. Whereas 'death with dignity' first emerged as a compassionate response to the threat of overtreatment, patients now face the threat of under-treatment because of the pressures to contain the escalating costs of health care ...

Some fear that the 'right to die' will be transformed into the 'obligation to die,' perhaps against the patient’s wishes and interests.

Some regard the provision of hydration and nutrition as basic care which should always be provided unless the patient’s imminent death is inevitable. Others make a distinction between the insertion of a feeding tube – which is classed as treatment – and the provision of nutrition and hydration through the tube, which is considered basic care. From this perspective, there are subtle differences between a decision not to insert a feeding tube, or not to reinsert it if it becomes dislodged, compared with a decision to stop providing nutrition and hydration through an existing tube. There is, however, no such distinction in the law - artificial nutrition and hydration are disqualified as life-sustaining measures in acute emergencies, and, as such, cannot be withheld or withdrawn without consent.

Although artificial nutrition and hydration are referred to in these guidelines together, there are good clinical reasons why the provision of each should be assessed separately. For example, with some terminally ill patients, subcutaneous intravenous fluids may avoid dehydration, decrease pressure sore risk and aid comfort, but the provision of nutrition artificially would be too invasive to be in the patient’s best interests. With other patients it is appropriate for both nutrition and hydration to be withheld or withdrawn.

Medical officers are required to seek a second clinical opinion before withholding or withdrawing artificial nutrition or hydration from patients whose death is not imminent. This opinion should be sought from a senior medical officer/consultant with experience of the patient’s condition and who is not directly involved in the patient’s care. This is to ensure that in this most sensitive area, the patient’s interests have been thoroughly considered and reassurance given to the patient’s family.

Adult patients with capacity are entitled to refuse artificial nutrition and/or hydration, and their refusals must be respected. Although patients are not obliged to justify their decision to refuse artificial hydration and/or nutrition, health professionals should try to ensure they have fully understood their situation and are not under any misapprehension about the nature of the treatment or the implications of their refusal.

It is not considered suicide to refuse artificial nutrition and hydration. Everyone has the right to refuse or discontinue a medical treatment. A person at the end of life is dying, not by choice, but because of a particular condition or disease. It is not considered suicide to refuse or stop a medical treatment that will not restore the patient to a level of health they would find acceptable.

Provided it is able to achieve its physiological aim, artificial nutrition and/or hydration should never be withheld or withdrawn from a patient with capacity who has expressed a wish to remain alive. The provision of artificial hydration and/or nutrition in these circumstances will benefit the patient, at least in the short term, by alleviating their distress.

The law acknowledges the exceptional difficulty of decision-making in this area by always requiring consent to withhold and or withdraw artificial hydration and nutrition.

5.5 Assisted ventilation

Assisted ventilation is a method used to mechanically assist or replace spontaneous breathing when a patient is unable to do so on their own. The methods for delivering assisted ventilation can be invasive or non-invasive. An example of an invasive method for artificial respiration (as it is sometimes called) occurs when an endotracheal or tracheostomy tube is inserted into the patient to deliver air directly to their lungs. Invasive ventilation methods most often occur in acute care settings for a short period of time. Sometimes patients with chronic lung conditions may require long-term assisted ventilation that they can achieve at home under the care of respiratory specialists.

The main form of mechanical ventilation is positive pressure ventilation that increases the pressure in the patient’s airway by forcing additional air into their lungs. Whilst assisted ventilation is identified as a life-sustaining measure, it can also create adverse side-effects, including pneumothorax, airway injury, laryngeal trauma, alveolar damage and ventilator-associated pneumonia.

Assisted ventilation is usually intended to provide assistance for breathing for limited periods of time. It is not a cure for a disease - even a lung disease. Assisted ventilation is one of the most common life-sustaining measures given to dying patients. Common medical indications for use include:

- acute lung trauma (including acute respiratory distress syndrome - ARDS)
- apnoea with respiratory arrest, including cases from intoxication

53 A recent decision in Hunter and New England Area Health Service v A 120091 NSWSC 761 upheld the supremacy of individual’s rights in a case involving a quadriplegic patient who requested removal of artificial hydration and nutrition.
- chronic obstructive pulmonary disease (COPD)
- acute respiratory acidosis with partial pressure of carbon dioxide, which may be due to paralysis of the diaphragm from such things as spinal cord injury, or the effect of anaesthetic and muscle relaxant drugs
- increased work of breathing as evidenced by significant tachypnoea, retractions, and other physical signs of respiratory distress
- hypoxemia with arterial partial pressure of oxygen with supplemental fraction of inspired oxygen
- hypotension including arterial partial pressure of oxygen with supplemental fraction of inspired oxygen

In clinical terms, the primary goal of artificial ventilation is to improve gas exchange and reduce the work of breathing in patients with acute respiratory failure, without causing iatrogenic lung injury.\textsuperscript{54} It is also recognised in the literature that decision-making about whether to withhold or withdraw artificial ventilation is among the most difficult and complex in medicine. Some of these challenges relate to artificial ventilation being defined along the continuum of life-sustaining measures, including providing oxygen (in any form) to assist or replace breathing, for example, it could be that providing oxygen is a comfort measure.

Although it could be argued that limitation or removal of mechanical ventilation causes a more imminent demise than does limitation or removal of artificial nutrition, hydration, medications, or dialysis, the limitation of cardiopulmonary resuscitation and other critical interventions also can have as imminent a ramification. Thus, although relatively little of end-of-life care debates have centered specifically on mechanical ventilation, the distinctions between mechanical ventilation and other forms of life support technology are probably artificial and irrelevant.\textsuperscript{55}

Irrespective of definitional issues, decision-making about whether to commence or to continue assisted ventilation carries with it the same legal and ethical principles as apply to other life-sustaining measures. If the patient lacks capacity, consent will need to be obtained from the patient’s substitute decision-maker/s, clear communication will be required with those closest to the patient, and careful documentation of all decision-making processes will be essential. In acute emergencies, consent to provide oxygen to a patient who lacks capacity would not be required, unless the patient has (at a time when they had capacity) expressly refused to accept artificial ventilation. Again, as with other life-sustaining measures, if the treating medical officer is directly aware that a patient has expressed an objection to having artificial ventilation (in any form) withheld or withdrawn, consent will be required from the patient’s substitute decision-maker.

### 5.6 Blood transfusions

While blood transfusions are specifically precluded under the legislation as life-sustaining measures for the purposes of consent, they are still an important life-prolonging treatment, and therefore need to be addressed in the broader context of end-of-life care. Issues about blood transfusions generally arise when:

- a patient refuses a blood transfusion as part of an advance care planning discussion with their medical officer/s, or
- a substitute decision-maker/s refuses to consent to a blood transfusion for a patient without capacity, or
- a blood transfusion is specifically refused in a valid Advance Health Directive.

The difference between providing and withholding a blood transfusion within the context of life-sustaining measure should be kept in mind: there are differences in the decision-making pathway and the requirements in the law. Guidance will most often be required in circumstances where there is dispute, disagreement, or uncertainty about blood transfusions and the use of blood products for people who are Jehovah’s Witnesses. In particular, issues may arise when the health care team is uncertain of its position about a treatment decision, or when there is uncertainty as to the extent of the person’s commitment to the faith, the extent of their decision-making ability, and the rejection of blood transfusions.

An adult who has capacity has the right to refuse blood transfusions, and this decision must be followed. This is the position at common law and also under the Queensland Criminal Code. Where medical treatment (such as a blood transfusion) is provided against the decision of an adult with capacity, it amounts to an assault. The assault under the Criminal Code may give rise to either criminal charges or to a civil action for battery.

Where a patient does not have capacity and the clinical decision to provide a blood transfusion to save the life of the patient is made, there is no straight-forward decision-making pathway. In these circumstances, under the law a blood transfusion comes under ‘urgent health care’, not ‘life-sustaining measure in an acute emergency’. As with life-sustaining measures, however, if the medical officer is not aware of any objections to the blood transfusion being provided, consent will not be required, provided the decision is made immediately. However, where objections are known (and, arguably, a patient who is a member of the Jehovah’s Witness faith would fall in this category), consent will be required from the patient’s substitute decision-maker before administering the blood transfusion.

It is highly likely that patients who are of the Jehovah’s Witness faith will carry information to that effect. Many followers carry a ‘No Blood Card’ (reviewed annually). Some may even wear a bracelet identifying that they belong to that particular faith. Caution should be exercised in this area because simply carrying a card or wearing a bracelet of membership to the Jehovah’s Witness faith may not necessarily be sufficient evidence for a refusal of a blood transfusion. It is the law in Queensland that a blood transfusion is not permitted without the consent of either the patient (if they have capacity), or the substitute decision-maker/s (if the patient does not have capacity).

Within any faith there is a range of adherence to the religion’s stated precepts by its members. No person is wholly defined by their membership of a church, and membership of the Jehovah’s Witnesses should be considered as only one influence in forming a person’s views. A person’s adherence to the faith, especially in circumstances where there is no available card, requires investigation and verification. In cases where there is dispute or disagreement as to the person’s commitment to the faith and their opposition to blood transfusions, the Office of the Adult Guardian should be contacted if the patient lacks capacity. This is because it is likely that other life-sustaining measures may be required in addition to a blood transfusion.

Within practical limits, the wishes of a patient from the Jehovah’s Witness faith who has refused a blood transfusion must be fully explored by speaking with them directly without other members of the family or members of the faith present. For example, there is a possibility the patient may change their mind when faced with the likelihood of serious disability or death.

In addition, the Jehovah’s Witnesses’ religious understanding does not absolutely prohibit some procedures. The medical officer in charge must make a considered judgement if an adult Jehovah’s Witness patient lacks capacity and there is no time to consult a substitute decision-maker/s for any of the following:

- Small blood fractions such as immunoglobulins, haemophilic preparations, albumin, cryoprecipitate, SPPS.

---

56 Queensland Criminal Code 1899, s. 246, s. 282A and s. 290
• The following surgical techniques on the condition that there is a continuous extra-corporeal circuit: haemodilution, heart-lung dialysis, intra and post-operative blood salvage and reinfusion, and renal dialysis.

• There are also a number of IV fluids that are acceptable for use with Jehovah's witnesses patients, for example:
  - Normal saline
  - Gelafusin
  - Rheomacrodex
  - Macrodex
  - Vamin & glucose
  - Hypotonic saline
  - Synthamin
  - Dextrose
  - Dextrose-saline
  - Hartmann’s solution
  - Ringer’s solution

A number of high-profile national and international cases serve as a reminder for medical officers to not provide blood transfusions without the explicit consent of patients. For example, in 1979, the Supreme Court of Ontario, Canada in the now well-recognised case of Malette found that a medical officer who administered a blood transfusion in an emergency to a patient carrying a card indicating her wishes not to have a blood transfusion, had committed an assault and was liable to damages. This was despite the blood transfusion having been administered in emergency circumstances, being done conscientiously and appropriately in terms of her medical condition, and consequently saving her life. The trial judge and the Supreme Court both found that an assault had taken place and awarded damages against the medical officer. It should also be noted that in some other cases, Jehovah’s Witness patients have failed in claims of battery.

It is recommended that where a medical officer believes that providing a blood transfusion to an incapacitated patient known to have expressed an objection to the measure (for example, as a Jehovah’s Witness) would be consistent with good medical practice, a second opinion from a more experienced clinician must be sought. Where time permits, consideration should also be given to contacting the Office of the Adult Guardian in these circumstances.

Queensland Health has a consent form (available on QHEPS) for blood transfusions that must be completed before giving a blood transfusion to an adult patient. This consent form is essentially a waiver should a blood transfusion be refused.

To assist with the decision-making process, the following questions are prompts for decision-making where a patient lacks capacity:

1. Does the patient carry a ‘No Blood Card’?
2. Does the patient have a valid Advance Health Directive refusing blood transfusions?
3. Has the person appointed an Enduring Power of Attorney/s with or without instructions regarding blood transfusions?
4. Has the person left instructions with members of the family regarding blood transfusions?
5. Has the person left instructions with their general practitioner regarding blood transfusions?
6. Has the person been a practising member of the Jehovah’s Witness faith, or have an association with a church, congregation or minister, and could any of these sources verify their adherence to the practice of no blood transfusions?
7. Has the health care team explored the possibility of alternate products such as blood expanders or alternate treatments to blood transfusion, when these products or treatments may be acceptable to Jehovah’s Witnesses?

57 Adults can also consent to blood transfusions under s. 17 of the Transplantation and Anatomy Act 1987
Clinical Considerations – Summary Points

General
1. Medical officers are expected to base their practice of medicine on some fundamental principles, including: integrity, truthfulness, fidelity, compassion, confidentiality, patient-centeredness, communication and clinical judgement. The key object of the practice of medicine is to serve the best interests of the patient.
2. Medical officers are obliged to consider the patient as a unique individual.
3. Where doubt exists over a diagnosis or prognosis, advice should be sought from a senior clinician with experience of that condition before making decisions about withholding or withdrawing life-sustaining treatment.
4. Treatment should never be withheld merely on the grounds that it is easier to withhold treatment than to withdraw treatment which has been initiated.

Resuscitation planning
5. Resuscitation planning is intended for patients considered to be at risk of cardiac and/or respiratory arrest in the foreseeable future.
6. Discussing resuscitation planning with/for patients who are not acutely ill, is likely to be inappropriate and could be misinterpreted.
7. If no explicit decision has been made in advice about resuscitation, if the wishes of the patient are unknown, and if uncertainty exists about diagnosis or prognosis, there is a presumption that all reasonable attempts will be made to revive the patient.

Cardiopulmonary resuscitation
8. Where no explicit decision has been made in advance, there should be an initial presumption in favour of CPR.
9. Decisions about CPR must be made on the basis of an individual assessment of each patient's case.
10. The benefits of prolonging life with CPR must be weighed against the potential benefits to the patient.
11. Before making treatment plans about CPR, all efforts must be made to contact those closest to the patient, and/or the patient's statutory health attorney. If this is unsuccessful, the Office of the Adult Guardian should be contacted, as circumstances permit.
12. Ensuring that a decision about CPR is made in advance is preferable to making decisions in a crisis.

Artificial hydration and/or artificial nutrition
13. Consent is always needed to withhold and withdraw artificial hydration and nutrition.
14. Patients are not obliged to justify their decision to refuse artificial hydration and/or nutrition, but health professionals should try to ensure that they understand the implications of their refusal.
15. It is not considered suicide to refuse artificial nutrition and hydration.

Assisted ventilation
16. If a patient lacks capacity, consent will be needed from the substitute decision-maker/s before making treatment decisions regarding artificial ventilation.
17. In acute emergencies, consent to provide oxygen to a patient who lacks capacity would not be required, unless the patient has (at a time when they had capacity) expressly refused to accept artificial ventilation.

Blood transfusions
18. Where medical treatment such as a blood transfusion is given against the decision of an adult with capacity, it potentially constitutes assault.
19. Queensland Health has a consent form (available on QHEPS) for blood transfusions that must be completed before giving a blood transfusion to an adult patient. This will apply to a patient if they have capacity or their substitute-decision-maker if they do not.
Appendix 1

End-of-Life Care: Decision-making for Withholding and Withdrawing Life-Sustaining Measures from Adult Patients

Part 2 - Ethical and Special Considerations (TOC)

Table of Contents

1.0 INTRODUCTION
   1.1 Community expectations
   1.2 Autonomy and Obligation
   1.3 Principles for decision making and quality care at end of life

2.0 BEST INTERESTS
   2.1 The Health Care Principle
   2.2 Patients without capacity

3.0 PATIENTS’ RIGHTS TO KNOW AND CHOOSE
   3.1 Respecting and following patient choices
   3.2 Patient’s right to refuse treatment
   3.3 Directions for treatment refusals in an Advance Health Directive
   3.4 Informed consent

4.0 FUTILE MEDICAL TREATMENT
   4.1 Futile medical treatment and euthanasia – the difference
   4.2 Futile medical treatment and the law generally
   4.3 Futile medical treatment and Queensland’s laws
   4.4 Difference between withholding and withdrawing life-sustaining treatment

5.0 MORAL QUESTIONS
   5.1 What is benefit?
   5.2 How can risk of harm be minimised?
   5.3 What is the meaning and value of death?
5.4 Can health professionals object to treating a patient on the basis of conscience?

5.5 Can resource allocation be used as a justification for withholding or withdrawing medical treatment?

5.6 Euthanasia

5.7 Assisted suicide

6.0 SPECIAL CONSIDERATIONS

6.1 People with special needs

6.1.1 The elderly

6.1.2 Children and adolescents

6.1.3 People with disabilities

6.1.4 Mental health patients

6.1.5 Indigenous and Torres Strait Islander people

6.1.6 People from other cultures

6.2 Organ and tissue donation

7.0 ADVANCE CARE PLANNING FOR PATIENTS AT THE END OF LIFE

7.1 National Framework for Advance Care Directives

7.2 The decision-making pathway

Glossary

Bibliography
Appendix 2

Excerpt of Speech (Hansard 17 October 2001): GUARDIANSHIP AND ADMINISTRATION AND OTHER ACTS AMENDMENT BILL, Hon. R. J. WELFORD (Everton—ALP) (Attorney-General and Minister for Justice) (11.41 a.m.):

“The decision to withhold or withdraw life-sustaining measures affects the lives of the most vulnerable people in our community. For this reason the bill contains special procedures for when life-sustaining measures may be stopped or not commenced. The amending bill essentially reflects what all Queenslanders would expect to occur at the end of their life. That is, where the health provider considers that commencing or carrying on life-sustaining measures is inconsistent with good medical practice those measures may be stopped if a guardian or attorney has consented.

This bill allows for family based decision making so that instead of forcing family members to go to the tribunal to get consent for a decision that they and the adult’s medical officers have made, the family can consent to the medical officer ceasing life-sustaining measures. This bill also provides safe and transparent decision-making practices for those people with a disability, by ensuring a person independent of the health provider must be consulted, except in an emergency, when end-of-life decisions are made.

This bill is also concerned with ensuring that the accepted practices of the medical profession developed over a very long time, reflective of the highest ethical principles, are set out in the legislative scheme that protects the most vulnerable in our society. There are a series of common law decisions where the courts have stated plainly that a medical officer commits no criminal offence when futile treatments, interfering with the dying process, are stopped. These legal decisions also reflect established theological and ethical teachings on these issues.

The bill also ensures that a health provider may act in an emergency to stop or not commence life-sustaining measures. Again, there is a requirement that the acts of the health provider be in accordance with good medical practice. The acute emergency provision will only apply to the life-sustaining measures of cardiopulmonary resuscitation or assisted ventilation. The acute emergency provision will ensure that adults with impaired capacity do not have to be subjected to invasive or unnecessary treatments when good medical practice demands that such treatment should cease immediately.

Recognising that people can differ about end-of-life decisions, the bill also provides for mechanisms to resolve disputes about the decisions to be taken. If there is a dispute between family members about what decision should be made, a health provider can refer the family to the Adult Guardian. The Adult Guardian can mediate between family members, take on the decision-making role, or seek instructions or help with his decision from the tribunal. Any family member, or other interested person, can also make application to the tribunal for orders or directions. The bill expressly preserves to the tribunal the continuing power to consent to the withholding and withdrawing of life-sustaining measures.

Nothing in this bill will interfere with the inherent jurisdiction of the Supreme Court to make decisions and protect people who have impaired capacity. The bill provides that both the consent of the Adult Guardian and the tribunal, like the consent of guardians or attorneys, is only operative when the health provider reasonably considers that the commencing or carrying on of life-sustaining measures is inconsistent with good medical practice. The bill will require that all decisions be properly documented by the health provider in the patient’s records.”
Possible triggers for initiating an Acute Resuscitation Plan*

(*Based on the Gold Standards Framework - Prognostication for specific clinical indicators of advanced disease)

**Cancer patients**

Any patient whose cancer is metastatic or not amenable to treatment, with some exceptions – this may include some cancer patients from the time of diagnosis e.g. lung cancer. ‘The single most important predictive factor in cancer is performance status and functional ability’

For patients with a prognosis of 12 months or less to live (NB: If patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less).

**Heart disease – Chronic Heart Failure (CHF)**

At least two of the indicators below:

- CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion
  - Patient thought to be in the last year of life by the care team - the ‘surprise’ question for less than 12 months
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical or psychological symptoms despite optimal tolerated therapy

**Chronic Obstructive Pulmonary Disease (COPD)**

- Disease assessed to be severe e.g. (FEV<sub>1</sub> <30%predicted – with caveats about quality of testing)
- Recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations)
- Fulfils Long Term Oxygen Therapy Criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level or confined to house through breathlessness
- Signs and symptoms of right heart failure
- Combination of other factors e.g. anorexia, previous ITU/NIV/resistant organism, depression
- >6 weeks of systemic steroids for COPD in the preceding 12 months
- The ‘surprise’ question applies for less than 12 months

**Renal Disease**

Patients with stage 5 kidney disease who are not seeking or are discontinuing renal replacement therapy. This may be from choice or because they are too frail or have too many co-morbid conditions.

- Patients with stage 5 chronic kidney disease whose condition is deteriorating and for whom the 12 month ‘surprise question’ is applicable i.e. overall, would be surprised if they were to die in the next year?

Clinical indicators:

- CKD stage 5 (eGFR <15 ml/min)
- Symptomatic renal failure -Nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload)
- Increasingly severe symptoms from co morbid conditions requiring more complex management or difficult to treat

NB. many people with Stage 5 CKD have stable impaired renal function and do not progress or need RRT.
## Liver Disease

- PT > 5 sec above control or INR > 1.5
- Serum albumin < 2.5 g/dl
- Refractory ascites
- Spontaneous bacterial peritonitis
- Hepatorenal syndrome
- Encephalopathy with asterixis, somnolence, coma
- Recurrent variceal bleeding

## Motor Neurone Disease

MND patients should be included from the time of diagnosis, as it is a rapidly progressing condition

Indicators of rapid deterioration include:

- Evidence of disturbed sleep related to respiratory muscle weakness in addition to signs of dyspnoea at rest
- Barely intelligible speech
- Difficulty swallowing
- Poor nutritional status
- Needing assistance with ADL's
- Medical complications eg., pneumonia, sepsis
- A short interval between onset of symptoms and diagnosis
- A low vital capacity (below 70% of predicted using standard spirometry)

## HIV/AIDS

- CD4 < 25 cells/ul or persistent viral load > 100,000 copies/ml
- Antiretroviral therapy no longer effective or desired
- Wasting syndrome
- PML (progressive multifocal leukoencephalopathy
- Cryptosporidiosis
- MAC (Mycobacterium avium complex), unresponsive to treatment
- Visceral Kaposi's sarcoma, unresponsive to treatment
- Toxoplasmosis, unresponsive to treatment

## Amyotrophic Lateral Sclerosis

Indications of deterioration and possible triggers for initiating an ARP

- Rapid progression of disease
- Intake insufficient to sustain life
- Significant dyspnea, on O2 at rest
- Declines artificial ventilation
- Medical complications, such as pneumonia or sepsis

## Coma - Any Etiology

- Abnormal brain stem response
- Absent verbal response
- Absent withdrawal response to pain
- Serum creatinine > 1.5 mg/dl
**Parkinson’s Disease**
The presence of two or more of the criteria in Parkinson disease are possible triggers for initiating an ARP:
- Drug treatment is no longer as effective/ there is an increasingly complex regime of drug treatments
- Reduced independence, need for help with daily living
- Recognition that the condition has become less controlled and less predictable with ‘off’ periods
- Dyskinesias, mobility problems and falls
- Swallowing problems
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)

**Multiple Sclerosis**
Indications of deterioration and possible triggers for initiating an ARP:
- Significant complex symptoms and medical complications
- Dysphagia (swallowing difficulties) is a key symptom, leading to recurrent aspiration pneumonias and recurrent admissions with sepsis and poor nutritional status
- Communication difficulties e.g. Dysarthria plus fatigue
- Cognitive impairment, notably the onset of dementia
- Breathlessness may be in the terminal phase

**Frailty**
Indications of deterioration and possible triggers for initiating an ARP:
- Multiple comorbidities with signs of significant impairment in day to day functioning
- Deteriorating functional score eg EPOC/Karnofsky
- Combination of at least 3 symptoms of: weakness, slow walking speed, low physical activity, weight loss, reduced weight loss, self reported exhaustion

**Dementia**
- Diagnosis of Alzheimer’s Disease
- Progressive degeneration of bodily functions including:
  - Unable to walk without assistance
  - Urinary and faecal incontinence
  - No consistently meaningful verbal communication
  - Unable to eat without assistance
  - Unable to dress without assistance
- Barthel score < 3/30
- Reduced ability to perform activities of daily living, plus any one of the following:
  - 10% weight loss in previous six months without other causes
  - pyelonephritis or UTI
  - serum albumin 25 g/l
  - severe pressure scores eg stage III/IV
  - recurrent fevers
  - reduced oral intake/weight loss
  - aspiration pneumonia

**Stroke**
- Minimal conscious state/dense paralysis/incontinence
- Medical complications
- Lack of improvement within 3 months of onset
- Significant cognitive or functional impairment
- Post-stroke dementia

### Functional scores - Karnofsky Performance Status Score

The Karnofsky score measures patient performance of activities of daily living. Score Function:

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Normal, no evidence of disease</td>
</tr>
<tr>
<td>90</td>
<td>Able to perform normal activity with only minor symptoms</td>
</tr>
<tr>
<td>80</td>
<td>Normal activity with effort, some symptoms</td>
</tr>
<tr>
<td>70</td>
<td>Able to care for self but unable to do normal activities</td>
</tr>
<tr>
<td>60</td>
<td>Requires occasional assistance, cares for most needs</td>
</tr>
<tr>
<td>50</td>
<td>Requires considerable assistance</td>
</tr>
<tr>
<td>40</td>
<td>Disabled, requires special assistance</td>
</tr>
<tr>
<td>30</td>
<td>Severely disabled</td>
</tr>
<tr>
<td>20</td>
<td>Very sick, requires active supportive treatment</td>
</tr>
<tr>
<td>10</td>
<td>Moribund</td>
</tr>
</tbody>
</table>

### Functional scores - WHO/ ECOG Performance Status

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, eg., light housework, office work</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of self care but unable to carry out work activities: upright more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self care, confined to bed or chair more than 50% of waking hours</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled, cannot carry on any self care, totally confined to bed or chair</td>
</tr>
<tr>
<td>5</td>
<td>Dead</td>
</tr>
</tbody>
</table>

Please note: that while this Prognostication Chart can be used to inform when an Acute Resuscitation Plan can be initiated, it is currently under review.