

Clinical Excellence Division



Advance Care Planning

Clinical Guidelines

January 2018



Advance Care Planning Clinical Guidelines

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An electronic version of this document is available at <https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/patient-safety/end-of-life/guidelines>

Other contact information and guidance about care at the end of life can be found at <https://www.health.qld.gov.au/careatendoflife>

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A quick note about standalone resources referred to in these guidelines:

Stand-alone resources developed for this guideline are available to download from the [Care at the End of Life](#) website. Downloading resources from the website (or by clicking on the pins below) will provide enhanced graphics. It is recommended the handouts be printed in colour, if possible. They include:

-  [ACP Quick Guide – possible triggers for initiating advance care planning](#) (Appendix 7)
-  [Advance care planning six step process](#) (Appendix 2)
-  [Decision-making flowcharts to obtain consent](#) (Appendix 8) (includes emergencies)

Also note that the [End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients - Guidance for health professionals](#) is also available from the [Care at the End of Life](#) website.



Purpose and scope

The purpose of the Advance Care Planning Clinical Guidelines for Queensland Health Clinicians (Guidelines) is to establish best practice principles for health professionals and services that embed Advance Care Planning (ACP) into routine practice. The Guidelines are also intended to provide high-level guidance to Hospital and Health Services (HHS) in the development of local policies and procedures to progress and expand the uptake of ACP for all ages and life stages across all service settings.

The information contained in these Guidelines is general in nature and is not intended to replace clinical judgment or act as legal advice. ACP scenarios may be complex and health professionals must consider the individual persons' circumstances and seek additional clinical, legal or ethical advice as required.

What is advance care planning?

ACP is a person-centred approach for planning current and future health and personal care that reflects the person's values, beliefs and preferences. The process of ACP is collaborative and coordinated and aims to develop an understanding of the person's treatment and care goals in order to assist health professionals to better meet their needs. Effective ACP involves ongoing communication between the person, those closest to them, and a multidisciplinary healthcare team to optimise the person's current treatment, care, and quality of life. If the person becomes too unwell to participate in decision-making, the preparation gained through ACP will guide all those involved in the process to make decisions about health and personal care in the person's best interests.

While anyone can carry out ACP at any time, the nature and timing of ACP will often be driven by the person's care needs and may be influenced by their willingness to participate.

Ideally, ACP discussions should be initiated early for those with life-limiting illness to optimise the person's quality of life and minimise potentially burdensome and unwanted treatment.

ACP can include:

- assessing the person's current condition and likely prognosis
- establishing the person's health and personal goals, values and preferences
- discussing current and future treatment and personal care options
- identifying the person's decision-makers for a time when they might lack capacity for decision-making
- documenting treatment and care plans and ensuring they are appropriately communicated and available when needed
- assisting the person to formally document their wishes if they choose to do so
- coordinating treatment and care to reflect the person's goals, values and preferences.

ACP should be integrated into clinical practice and routine care, and reviewed regularly to ensure plans remain consistent with the person's values, beliefs and preferences for health and personal care.



Introduction

The landscape for ACP is changing; previously, greater attention was paid to individuals completing formal documents for a time in the future when they might lose capacity for decision making and decisions are required about their treatment and care.¹ Often, the key performance benchmark for ACP programs was document completion rates, despite there being no guarantee they improved care at the end of life or corresponded to an individual's future care preferences.^{2, 3} The scope of ACP has been progressively expanded to include discussions that explore what the person values most in life in order to help guide both current and future treatment and care.⁴ Early ACP is now actively encouraged for healthy persons and those with early-stage disease so that discussions are held when the person is best able to participate, rather than deferring the process until deterioration occurs. Regardless of how ACP is understood and in which setting it occurs, best practice in the recent literature agrees that ACP should be proactive, integrated into routine care and undertaken as an iterative process.^{5, 6}

The shift in thinking towards more broadly framing ACP is overdue and welcome. Responding to this challenge brings new opportunities for a system-wide approach that more effectively identifies those who can benefit most. The progressive expansion from a focus on preparing for a potential loss of capacity to proactively planning for current and future treatment allows the person to actively participate throughout the ACP process while options are still available, and when circumstances allow, enables appropriate care and support to be arranged long before deterioration occurs. Contemporary best-practice ACP should, therefore, be seen as a key enabler of high quality person-centred care at the end of life.

Background

Over the twentieth century increasing community expectations that individuals have the right to make their own decisions, particularly in relation to health and personal care, has led the way for the introduction of guardianship schemes across the world. The historical context for ACP emerged from concerns about how people died, rather than what they died from. In particular, the high profile case of Karen Ann Quinlan⁷ became one of the defining moments in international public, political and legal debate around enabling those who can no longer communicate to have a voice. From the late 1960s onwards two clear themes emerged: it was no longer universally accepted that all available technology should be used to preserve life at any cost; and there was an increasing recognition of personal autonomy in healthcare decision-making. Since that time, the combination of guardianship regimes and the common law has sought to preserve the rights of individuals who lack decisional capacity and by allowing decision-makers to act on their behalf and in their best interests. Therefore, while the scope of ACP is changing its intent has remained constant. That is, ACP is founded on respect for individual autonomy and it advocates for a person's right to make choices about treatment and care at the end of life based on their own values, beliefs and preferences.

Our community now expects that they will be provided the opportunity to carry out ACP. This is supported in the following key documents:

- National Safety and Quality Health Service Standards (NSQHSS) – see [Appendix 1](#)
- Australian Government
 - [National Framework for Advance Care Directives](#)⁸
 - [National Consensus Statement: essential elements for safe and high quality end-of-life care](#)⁹
 - [National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life](#)¹⁰
- Queensland Department of Health
 - [Statewide strategy for end-of-life care 2015](#)¹¹
 - [Care at the end of life: Implementation Plan 2015-2025](#)



Care at the end of life – a snapshot for Queensland

While some people receive excellent care at the end of life, some do not. The failure to talk about and plan for death is one of the most significant obstacles to improving the quality of dying.¹²⁻¹⁴ The profile of death and dying has changed dramatically over the past century; people are now much less likely to die young, and far more likely to die in old age of chronic disease. In 2015, people aged 60 and over represented almost 85 per cent of all deaths in Queensland, had longer hospital stays and generally suffered more comorbidity, including dementia and illnesses with complex needs that required more specialised care. One third of all deaths in Queensland are also due to lifestyle related chronic conditions, with death being more predictable and often occurring after a long period of deterioration.¹⁵

It is clear from an understanding of the experience of patients whose deaths are expected, that there is more that can be done much earlier to improve their quality of life and to assist them to live more comfortably until they die. Unfortunately, Queenslanders are twice as likely to experience an institutionalised death compared to people living in New Zealand, the United States, Ireland and France,¹⁶ as over half of the almost 30,000 deaths in Queensland in 2014-15 occurred in hospitals.¹⁷ Even patients receiving palliative care services are highly likely to die in acute hospital settings.¹⁸ This data suggests that not enough is being directed towards helping people to die well and in a place of their choosing.

A good death

In the last year of life many people experience a healthcare system that is disconnected, confusing and fragmented. Their journey often winds through a complex medical maze of uncoordinated referrals to multiple health professionals. Disquiet with the status quo has driven support for the concept of planning for what is commonly termed a “good death”.¹⁹ While the notion of a good death is highly subjective, common elements are generally agreed to include any combination of the following:²⁰

Table 1 - A good death - core and sub themes

Core Theme	Subtheme
Preferences for dying process	How, where and control over who is present Preparation for death (e.g. attending to ‘unfinished business’, funeral arrangements) Support of cultural practices before and after death
Pain-free status	Not suffering Pain and symptom management ²¹
Emotional well-being	Emotional support and psychological comfort ²² Chance to discuss the meaning of death
Spirituality	Access to religious/spiritual comfort if desired Time to meet with spiritual advisers
Dignity	Respect as an individual person To be able to leave when it is time to go, and not to have life prolonged unnecessarily ²³
Life completion	Saying goodbye Strengthening relationships with loved ones ²⁴ Acceptance of death Achieving a sense of completion in life ²⁵
Treatment preferences	Access to information and expertise of whatever kind is necessary Retaining control over decisions and clear person-centred decision-making ²⁶



Core Theme	Subtheme
	Control over treatment and timing of death Being prepared for what to expect ²⁷ Being treated as a 'whole person' ²⁸ Seamless continuity of care across health care settings and home ²⁹
Quality of life	Preferences are respected and met where possible Acceptance, pleasure and gratitude Quality of life until death
Relationship with health care professionals	Trust/support/comfort from physician/nurse Physician comfortable with death/dying Discuss spiritual beliefs/fears with physician Effective patient-physician communication and physician-family communication ³⁰
Other	Physical touch Being with pets Grief and bereavement support before and after the death ³¹

[Source: Adapted from Swerissen, H. and Duckett, S. 2014, *Dying Well*. Grattan Institute. pp. 8-9; Smith, R. 2000. 'A good death', *British Medical Journal*, 320 (15 January) and Meier EA et al. 2016. Defining a good death (successful dying): Literature review and a call for research and public dialogue. *Am J Geriatr Psychiatry* 24(4). April 2016. 261-271]

Best practice advance care planning principles

Best practice ACP is underpinned by foundational clinical, ethical and legal principles, central to which is the importance of the autonomous individual and support of those closest to them. To guide health professionals in carrying out ACP in Queensland Health facilities the following ten principles, which build on the [National Framework for Advance Care Directives](#)³² are identified below:³³⁻³⁵

Best Practice ACP Principles

1. Adults are presumed to have capacity
2. Decisions are person-centred
3. Decision-making must reflect respect for life and the person's right to personal autonomy
4. Quality of life is defined by the individual
5. Care should be multidisciplinary in nature to meet the individual needs of the person and their family
6. Health decisions may be broad and can relate to any time in the future
7. All efforts will be made to obtain the appropriate consent through a collaborative approach
8. Substitute decision-maker/s make decisions in the person's best interests
9. Transparency and accountability for decision-making
10. ACP is more than planning for decisions about life-sustaining medical treatment at the end of life.



Why we should encourage advance care planning

Proactive ACP should be an integral part of day-to-day clinical practice and part of the role of all healthcare professionals.³⁶ Even before a person experiences deterioration due to a life-limiting illness, ACP can help to optimise a person's quality of life and allow the person and those closest to them to maintain a sense of control over their treatment and care.

ACP is much more than the identification of a decision-maker in preparation for a loss of decisional capacity and the documentation of whether or not cardiopulmonary resuscitation (CPR) should be attempted. The ACP process is a multidisciplinary approach that allows individuals to partner with the healthcare team in shaping the course of their care. ACP encourages all those involved in the person's treatment and care to agree on a unified care plan that reflects the person's preferences within the context of their beliefs, values and personal goals.

The evidence

Emerging evidence suggests that ACP achieves successful outcomes when associated with the broader aim to optimise current and future health care, rather than simply completing documents in anticipation of the loss of decisional capacity. Prospective observational studies and randomised trials have shown that ACP:

- reduces unnecessary aggressive treatments at the end of life, and results more often in care that is consistent with the person's goals^{37, 38}
- affects patient care in positive ways, for example being able to achieve a "good death" - treatment in final days, place of death, and funeral arrangements³⁹⁻⁴⁴
- achieves a higher satisfaction with quality of care⁴⁵
- reduces hospitalisations for patients at the end of life,⁴⁶ particularly for nursing home residents by between 40 per cent to 80 per cent and can lead to a threefold increase in palliative care referrals⁴⁷
- increases the likelihood that clinicians and families understand and comply with a person's wishes^{48, 49}
- diminishes the likelihood of stress, anxiety, and depression in surviving relatives⁵⁰
- improves the incidence family meetings with decision-makers when a person is at the end of life⁵¹
- invokes earlier initiation of more appropriate palliative care, which improves symptoms and mood, reduces undesired use of invasive interventions and life-sustaining treatments, lowers the likelihood of in-hospital death, prolongs life of higher quality and reduces use of resources that do not benefit patients^{52, 53}
- reduces moral distress among healthcare providers.⁵⁴

Detering and Silveria et al's (2017) recent analysis cite a 2014 study, which provides a systematic review of 113 papers on elements of ACP, consisting of predominantly observational studies.⁵⁵ The main findings from the Brinkman-Stoppelenburg et al (2014) paper included:



- ACP increased compliance with patients' preferences (three out of six studies)
- ACP increased quality of life for the patient and family (four out of four studies)
- The presence of a Do Not Resuscitate (DNR) order was associated with a decreased use of cardiopulmonary resuscitation (CPR), (four out of five studies) and an increased use of hospice and palliative care services (six out of six studies).
- The presence of a Do Not Hospitalize (DNH) order was associated with a reduction in the rate of subsequent hospitalizations (eight of nine studies), a decrease in life-sustaining treatments (three of three studies), and an increase in palliative care and/or hospice services (five out of five studies).
- Increased compliance with patients' end-of-life wishes (three out of four studies)
- A decrease in subsequent hospitalization (three out of three studies)
- A decrease in in-hospital deaths (three studies) and ICU deaths (one study) and an increase in in-home deaths (two studies)

(Source: From Detering K and Silveira KM. 2017)

When to carry out advance care planning

There is no specific or 'perfect' time to initiate the ACP process. However, there are times when it becomes more important, or even urgent, that the issue be addressed. Evidence-based clinical indicators that signal when ACP could be initiated are well-established in the literature. [Appendix 2](#) provides a guide to identify those who are likely to benefit the most from ACP discussions. [Appendix 3](#) provides further detail about clinical indicators, including issues to consider under specific diseases and conditions.

While there is no standard time to offer ACP, the literature does agree that discussions are not a 'one-off'. They should be initiated early in the course of a person's illness, may involve a number of health professionals and generally take place over several consultations.^{56, 57} It is also recommended that ACP be carried out during routine outpatient appointments with a trusted health professional, when there is time for non-pressured deliberation.⁵⁸

Some commentators state it is preferable for the person to be medically stable and able to participate in the discussions,⁵⁹ however this may not be possible when the person is seriously ill and/or has a progressive illness; therefore, it is never too late to attempt ACP discussions.

The literature indicates that when the person becomes acutely unwell, it is helpful to tell them that normally more time is allowed for such discussions, but that current circumstances do not allow it.⁶⁰ This is particularly the case when the need to discuss resuscitation planning and life-sustaining medical treatment arises. A systematic review that evaluated discussions relating to resuscitation planning for appropriate patients identified two key themes:⁶¹

1. it is beneficial to begin resuscitation planning at the time of admission, and
2. end-of-life decision-making can be assisted by involving the person early in ACP discussions even when they are clinically stable and curative treatment may be indicated.

The review by Field, Fritz et al (2014) also concluded that:

"...linking decisions about resuscitation to discussions about overall treatment plans provided greater clarity about goals of care, aided communication between clinicians and reduced harms. Standardised documentation proved helpful for improving the frequency and quality of recording decisions."⁶²



Queensland Health has a medical order form called an Acute Resuscitation Plan (ARP) that allows for the documenting of resuscitation planning. The document [End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients - Guidance for health professionals](#) provides further detail about resuscitation planning and completing the ARP form. There is also brief discussion about the form in the section on [ACP documentation](#) below.

A variety of triggers may prompt even a well person to think about or carry out ACP, such as hearing about it in the media, the death of someone close, a change in personal circumstance or reduced quality of life for any reason. Other moments when it is appropriate to initiate discussions and introduce the concept of ACP, are:

- when the person or a member of their support network raises concerns about current and future treatment and care
- if a person expresses existential concerns about the future after a significant event, such as retirement or declining health of a spouse
- part of routine care after the diagnosis of a life-limiting condition or disability
- unexpected exacerbations in a person's condition that causes prognosis to be less certain.

Impact of delayed planning for care end of life

Delayed end-of-life decision-making has led to a number of adverse outcomes including:

- continued burdensome, unwanted and/or futile medical interventions (e.g. CPR, chemotherapy or surgery) for those approaching end of life, including those who are imminently dying
- poor experiences for families where distressed family members are called on to engage in end-of-life decisions while they are grieving, or who experience anguish observing futile and/or unwanted life-sustaining measures in their dying loved one
- potentially avoidable conflicts within families, or between families and the healthcare team, or within the health care team, about the best course of treatment and care for the dying patient
- care being delivered in acute settings when better patient outcomes could be delivered in supported community or home environments
- stress for health professionals balancing their obligation to act in the best interests of dying patients, while reconciling sometimes differing views amongst treating clinicians and families about what that entails, and ensuring good stewardship of health resources.

[Adapted from NSW Health. Advance Planning for Quality Care at End of Life – Action Plan 2013–2018]

When to carry-out ACP - summary

- discussions are not a 'one-off'
- discussions should be:
 - initiated early in the course of a person's illness
 - may involve a number of health professionals and clinical streams
 - generally take place over several consultations
- discussions are best carried out:
 - in routine outpatient appointments
 - with a trusted health professional
 - when there is time for non-pressured deliberation
- it is preferable for the person to be medically stable and able to participate in the discussions
- it is never too late to commence ACP



Advance care planning process

The ACP process is an iterative and dynamic process that enables the person to plan for current and future treatment and care. ACP will be experienced differently according to the unique circumstances of each individual and the process can be entered into at any stage. While those who are fit and healthy can carry out ACP, more often those who engage in ACP are dealing with a new diagnosis or deteriorating health. Many have also become more aware of their prognosis through their encounters with the health system. For people who are marginalised, ACP is shown to be an empowering experience, particularly for the frail elderly.⁶³ Embedding ACP as part of routine care gives people opportunities to discuss and review their preferences over time without pressure. Throughout the ACP process, health professionals will need to review care plans and other ACP documentation from time to time, particularly when the person's health, goals of care or other circumstances change.

Six steps to carry out ACP to guide clinical practice are identified:

[Step 1 - Identify](#)

[Step 2 – Assess](#)

[Step 3 – Discuss](#)

[Step 4 – Plan](#)

[Step 5 – Coordinate](#)

[Step 6 – Review](#)

[Appendix 4](#) contains a two-page representation and summary of the six step ACP process described below. Careful documentation of the outcomes of discussions is required at all stages of the ACP process. As ACP is dynamic and non-linear, documents should be reviewed frequently and the responsibility for initiating review clearly identified. This resource can also be downloaded on the [advance care planning](#) page on the [care at the end of life](#) website.

Step 1 - Identify

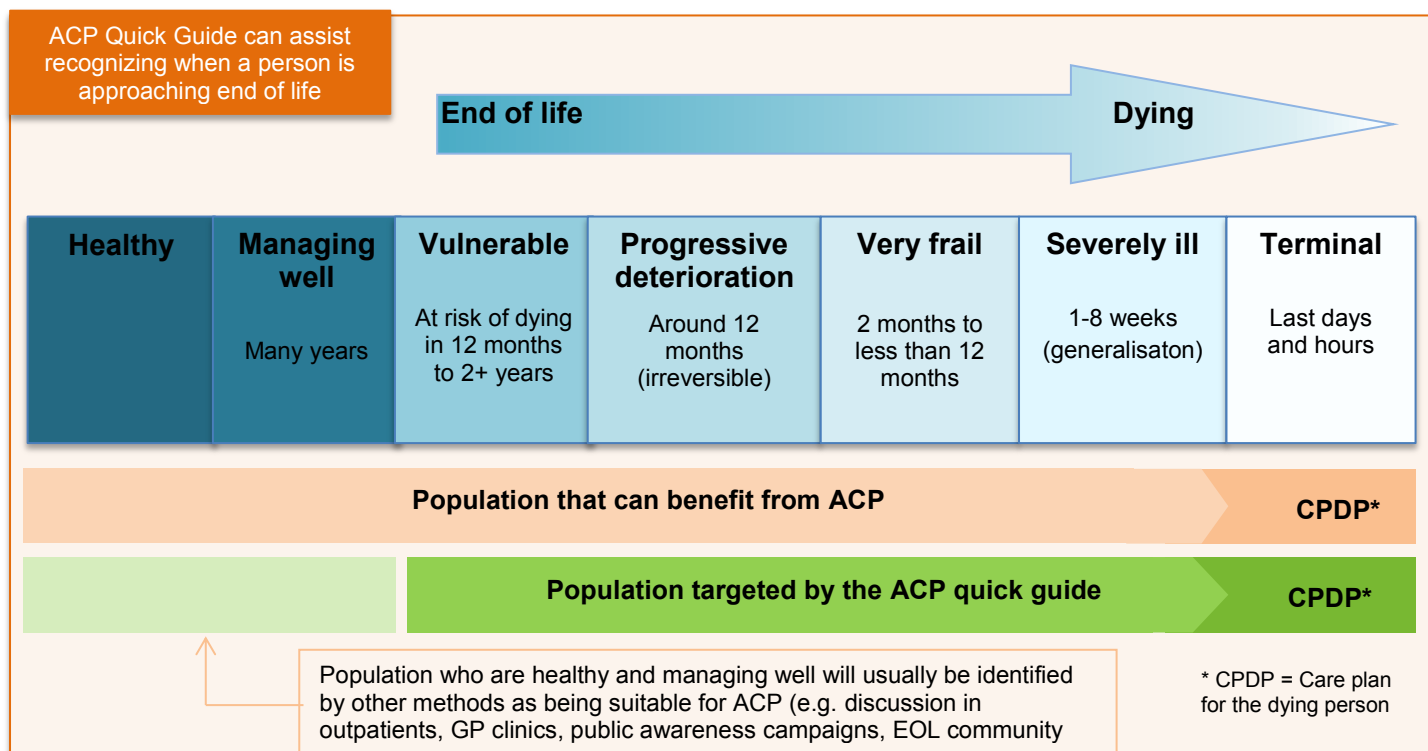
The first step in the ACP process is to identify those who are most likely to benefit from ACP so they may participate to the greatest extent possible in managing their treatment and care as their condition deteriorates. Why is identifying *'the who'* so important? Some deaths are unexpected, but evidence shows that many more can be predicted. Recognising the population most at risk of dying and commencing ACP early, irrespective of the diagnosis, can help people to receive well-coordinated, high-quality care and, importantly, assist them to achieve treatment and care goals that align with what they value most in life. Identifying those at risk of dying and commencing ACP early in the disease trajectory also reduces the risk of potentially burdensome and unnecessary medical treatment being provided at the end of life.

While any person can participate in ACP, even if they are healthy and otherwise well, key groups within the general population broadly identified as benefiting most from early ACP include people of any age who:

- are diagnosed with a life-limiting illness or disability
- have multiple comorbidities and are at risk of deterioration
- have early and/or mild cognitive impairment
- manifest general indicators of frailty
- are living with chronic progressive deterioration of disease
- are approaching the end of their life.



[Appendix 2](#) provides a guide to identify those who are likely to benefit the most from ACP discussions. The *ACP Quick Guide* is designed to identify people who are at the end of life, but before significant deterioration of their condition occurs. A single page of broad indicators supports health professionals to identify whether the person in their care is at the end of life and the potential for further decline. The graphic below illustrates the end-of-life population targeted by the guide.



[Appendix 3](#) provides further detail about clinical indicators, including examples of issues to consider under specific diseases and conditions. [Appendix 4](#) is the stand alone six step two-page ACP process. Useful tools to assess functional capacity appear at [Appendix 5](#).

Special considerations for advance care planning

The ACP process is not one-size-fits-all and needs to be adapted to meet the specific needs of disadvantaged individuals and groups. Groups that require special consideration include:

1. children and young people
2. Aboriginal and Torres Strait Islander people
3. people from culturally and linguistically diverse backgrounds
4. people with mental health challenges
5. people with disabilities
6. lesbian, gay, bisexual, transgender and intersex people.

For further information about these special considerations when conducting ACP, refer to [Appendix 6](#).



Step 2 - Assess

The focus of the ACP assessment is on anticipating a person's likely needs so that the right treatment, care and support can be provided at the right time. This proactive focus optimises opportunities to provide care that is consistent with an individual's goals, values, beliefs and preferences.

Prior to initiating ACP discussions health professionals should assess:

- the person's current condition, likely prognosis, treatment options and the potential burdens and benefits of those options to help frame ACP discussions
- whether the person has carried out ACP in the past; completed any ACP documents; has ACP documents with them and/or on file
- whether previous ACP discussions or formal documents (such as a person's advance health directive (AHD) apply to the current circumstances
- whether the person has or should have an ARP
- the person's capacity for decision-making and likely health trajectory – particularly important if the person is diagnosed with conditions likely to affect cognitive ability
- the need for other decision-makers to be involved if the person lacks capacity
- if the person has disabilities that need to be taken into consideration, the need for coordination of arrangements with relevant care/community agencies
- the potential for preventative measures that may improve the person's quality of life and risk of early mortality.
- if the person has any communication difficulties and whether assistive communication devices or health professionals experienced in supporting communication (e.g. speech pathologists, audiologists, occupational therapists) are required.

Assessing capacity

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

1. The person understands the basic medical situation.
2. The person understands 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. The person is able to use or weigh that information as part of the process of making the decision (for example, asking questions).
4. The person is able to communicate a decision (for example, by talking, using sign language or any other means).
5. The person is able to communicate the decision voluntarily (for example, is there an absence of coercion, undue influence or intimidation by the patient's family/decision-maker/s?).

These Guidelines do not recommend a preferred method to assess capacity, however there are some important considerations that have potential legal implications. Some of these include:



- 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 person's competence or capacity to make decisions.
- 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 personal or health matters.
- Capacity assessments involve more than just judging cognition and weighing objective scores of memory, concentration, attention and orientation. Capacity is also domain specific, and a person may have decisional capacity in some domains, for example deciding what to eat and wear, and not in others, such as managing medication or paying bills.
- In cases where people have borderline or fluctuating capacity or conditions that may affect cognition such as depression, it can be difficult to assess whether an individual can make valid decisions on very serious issues.
- Second opinions must be obtained where doubt exists about a person's level of capacity to make decisions about their own health matters at the time the decision is needed.
- When a decision is required, where it is possible and practicable, time should be allowed for a person to regain capacity to the extent this enables them to make decisions about health and personal matters (e.g. following a mental health episode, delirium from medication or other source).

Step 3 - Discuss

This phase in the ACP process is about the 'how' – how to have the discussions and what topics may be covered. ACP discussions are usually semi-structured, and while the exact approach and content of discussions will often vary depending on the person's needs, general advice regarding who should be present and how to create the right environment and generic communication skills are provided below.

Who may be involved in the advance care planning discussion

The person

Ideally, the person involved should be medically stable, have decisional capacity and be willing for an ACP discussion to occur. As discussed above, this is not always possible and should not prevent discussions from occurring when it is necessary either with the person to the level of their capacity and with their substitute decision-makers if they lack decisional capacity.⁶⁴

When the person involved does not have decisional capacity for the decision to be made now, their substitute decision-maker should be present, as this activates the guardianship laws (for more information, refer to the section on [substitute decision-makers](#)).

The person's family or friends

If the person consents, the person most likely to be their substitute decision-maker should be present where possible.⁶⁵ However, not all individuals will want to have a family member or friend with them and this should be determined with the person before each discussion.⁶⁶

If the person consents, other members of the person's family and support network may be invited to participate in all or some discussions.

Health professionals

Different health professionals may be involved in discussions at various points along the ACP process. These may include the person's GP, social worker, and medical specialist/s from other clinical streams.



In general, the number of clinicians should be kept to a minimum so as not to overwhelm the patient; however, larger numbers may be appropriate if ACP is being carried out within the context of a broader family meeting or case conference.

Particularly for more acute illness, most people prefer information to come from a confident expert (i.e. not delegated to the most junior person on the team).⁶⁷ Refer to [Appendix 7](#) for specific health professional's roles and responsibilities in relation to the ACP process.

If required, interpreters may also be present.⁶⁸ Ensure privacy and confidentiality of the person is maintained at all times. The [Queensland Government website](#) offers assistance in this area.

Setting and location

The setting should be conducive to the discussion. That is, it should be comfortable, quiet and private and take into account the person's unique circumstances.

Phones and pagers should be turned off or on silent and other potential interferences eliminated as far as is practicable to do so.

Communication skills for the discussion

Good communication skills will allow the person and others who may be present feel more comfortable and relaxed. Good generic communication skills include: ⁶⁹

- using eye contact (if culturally appropriate)
- using appropriate and non-threatening body language such as an open posture
- sitting close to the person rather than from behind a large table or desk and if possible, sitting at the same level rather than standing over the person
- listening actively, such as by nodding or making noises of agreement or encouragement to indicate understanding and providing time for the person to ask questions
- reflecting empathically – check with the person if you wish to clarify something
- showing compassion by using a warm, caring, and respectful manner
- using an empathic, person-centred style which also involves using open-ended questions with an emotional content.

Communication example – unwell but stable (e.g. after a stroke)

- *How do you feel things are going for you right now?*
- *Have you thought about how you would like to be cared for if you become more unwell?*
- *I think you'll recover well after this stroke. It's good that you've been doing the exercises given by the physiotherapist and the speech therapist. It has helped.*
- *As we've talked about, the warfarin, the drug which thins your blood will reduce your chance of having another stroke. But, unfortunately it does not reduce the chance of another stroke to zero.*
- *Would you like to talk about planning what we should do if you have another stroke?*
- *Do you have any questions or concerns about how we might care for you if your health gets worse?*
- *If you have another big stroke or your heart stops beating, we can treat you in a variety of ways.*
- *Have you thought about how you would like to be treated in such circumstances?*
- *Some people would like full resuscitation (CPR) while others would prefer just to be kept comfortable – there is no right or wrong.*
- *It is possible that, even if we did CPR, we might not be able restore you to your current state of health.*
- *There's a chance that we might end up with you not being able to talk and look after yourself.*
- *How would you feel about that? What would be important to you in terms of how we look after?*



Preparing for the discussion

There are also some important management and administrative matters that should be addressed when preparing for an ACP discussion, such as:⁷⁰

- ensuring the facts about the person's clinical circumstances are correct
- being familiar with the patient's clinical records to establish their current health status and also to determine that records are current
- speaking with relevant members of the multidisciplinary team to determine the extent of the patient's disease and relevant comorbidities
- gaining up-to-date knowledge about the patient's underlying illness and appropriate treatment options
- finding out what the patient has been told by other members of the multidisciplinary team in order to provide consistent information or to identify inconsistencies. This can include speaking with the referring specialist or general practitioner
- reviewing the social, emotional and psychological status of the person to gauge how they may respond to the ACP conversation but also what other psycho-social supports they may need during or after the conversation (some people welcome the ACP discussion but others may find it emotionally distressing)
- convening a case conference, if required
- allowing sufficient time for the discussion and to repeat information if it is not understood
- allowing time to confer with a more experienced colleague if the ensuing discussion is troubling or you need to de-brief.

What topics may be covered?

Many topics may be covered during ACP discussions. The mix will depend upon the person's unique circumstances and willingness to participate. Typically, ACP discussions occur over time and with different health professionals and cover the following topics:

- the person's wishes, preferences or fears in relation to their current or future treatment and care
- the feelings, beliefs or values that may be influencing the person's preferences and decisions
- the person's diagnosis, prognosis and questions about the goals of care
- family members, those close to the person or other substitute decision-makers that the person would like to be involved in decisions about their care
- resuscitation planning, involving a conversation about interventions that may be considered or undertaken in an emergency, such as CPR
- access and/or transition to other services, such as to palliative care or other community care services
- the benefits of ACP, such as when it may be helpful to make decisions in advance or appoint someone trusted to make decisions on the person's behalf
- formally documenting preferences for a time when decisional capacity becomes impaired
- the person's preferred place of care (and how this may affect the treatment options available)
- the person's needs for religious, spiritual or other personal support
- wishes in relation to funerals, the handling of their body (including cultural needs), and their beliefs or values about organ or tissue donation.⁷¹



How to introduce and discuss advance care planning

Not every ACP discussion will include every element and often the steps will not be linear. ACP discussions should be adapted to the person and their needs and circumstances *at the time*. Each person's circumstances are unique and different phases of the ACP process may be more relevant than others, and some may not even apply, such as if the patient is in the terminal phases of their condition.

It is also important to remember that no one should be coerced into considering or discussing ACP. Despite initiation of and access to ACP discussions, people may still choose not to carry out ACP in any form. Others may like to learn about their options and talk about their goals, wishes and values, but elect not to make or document specific decisions, entrusting this decision-making to someone close. For these reasons ACP should be regarded as an iterative, person-centred process that aligns with the person's unique needs and circumstances, and where the timing of discussions and finalisation of decisions is suitable to them.

As ACP discussions can be emotional and sometimes distressing for all concerned, if at any point the person indicates they do not wish to proceed for any reason, reschedule the discussion for a more suitable time. This can also form part of the consenting process to discuss ACP, by ensuring to check in with the patient to confirm they wish to continue. For further detail about consent, refer to [Queensland's legal framework](#) in [Appendix 8](#). Also refer to the Clayton J, Hancock K et al (2007) [guidelines](#) for detailed guidance about communicating prognosis and bad news. Some communication examples relevant to introducing ACP appear below.^{72, 73}

Communication examples: Introducing ACP

- *Have you heard about advance care planning before?*
- *The purpose of advance care planning is to ensure that you are cared for the way you would want to be, even when you are no longer able to communicate.*
- *Have you ever thought about the type of medical care you would like to have if you ever became too sick to speak for yourself?*
- *Do you know who would make decisions about your medical treatment if you were unable to make them for yourself? Is this the right person?*
- *Have you ever spoken about this to the person who will make decisions for you? Would you like to include them in these discussions, so they know what is happening and what might happen in future?*
- *Sometimes people with your type of illness lose the ability to make decisions [or communicate their wishes] as the illness progresses. Who would make decisions for you if you were unable to do this for yourself?*
- *Have you talked to your family or your GP about what you want?*
- *It's often easier to talk through tough decisions when there isn't a crisis.*
- *If the person can identify a potential substitute decision-maker: "Would you like to talk this through with them? Would you like me to assist you with this?"*
- *You may be aware that we have laws where people can choose someone who will make decisions for them and how this will happen if they are ever too unwell to be able to make their own decisions. Is that something you are interested in finding out about?*
- *Some people have thought about what they want and record their wishes in what is called an advance health directive. Do you have an advance health directive? Would you like to complete one? I could get you some more information if you like, or refer you to someone who could tell you more about this.*
- *These are discussions we may need to revisit if there are changes in the course of your illness.*



Step 4 - Plan

The planning phase of ACP focuses on identifying future health and care needs and involves the person in decision-making to the greatest extent possible. This phase can be challenging when an individual's response to treatment or prognosis is unknown or difficult to predict. There is, however, some ability to predict outcomes based on the natural history of life-limiting conditions. This makes it possible to explain what the person might experience as they deteriorate, and explore their expectations about how their current and future treatment and care should be managed.

When carrying out ACP, it is important to incorporate the person's values and goals of care into their treatment and care plans. It should be borne in mind that without the person's goals and preferences for medical treatment, health professionals may not have sufficient information for appropriate decision-making.

At all stages of the ACP discussion it is important to ensure open communication is maintained with the person and/or their decision-maker and steps taken to ensure good relationships are maintained with all involved. Planning for events that are yet to take place may be distressing if there are limited options available for the person's medical treatment and the focus is on decisions regarding resuscitation planning. Care should be taken to ensure that a sensitive and compassionate approach is maintained when addressing the subject of withholding and/or withdrawing life-sustaining measures.

The concept of shared decision-making can be incorporated during any stage of the planning process. This will assist to identify the goals of care to ensure the right care is given at the right time.⁷⁴

Goals of care

Goals of care is a term that can be used in a variety of contexts and is an important part of the planning phase of ACP. For care at the end of life, goals of care conversations consist of putting prior ACP conversations about values, beliefs and preferences into the current clinical context. Discussions about goals of care will include considering whether it is time to shift from curative to a palliative care approach to minimise or rationalise medical interventions and focus on therapies likely to increase patient comfort and improve quality of life.

When a goals of care discussion is successful, a collaborative plan of treatment and care emerges, guided by the patient's goals, values and preferences. While many goals of care discussions clarify the types of interventions to be initiated for patients, others address the possibility of withdrawing or withholding life-sustaining measures. It is always important to help families/friends differentiate between the decision to withhold or withdraw therapies from euthanasia/physician-assisted suicide as these are ethically distinct acts. For example, a doctor might need to explain that withdrawing or not escalating use of a particular intervention or therapy does not hasten the dying process but instead avoids extending life artificially and allows for a natural death.

Overall, empathetic, direct, and honest responses to questions and exploration of beliefs, fears, and emotions will help find common ground. Discussions that focus on goals of care take time and effort, but are worthwhile because they lead to improved quality of care and clearer, shorter, and more collaborative discussions and decisions as the patient's condition and needs change.

Advance care planning documentation

Whenever health professionals have an ACP discussion it is important to capture and appropriately document the outcomes in the person's clinical record. The person should also be introduced to the concept of formally documenting his or her own preferences, remembering that this step in the ACP process is optional and voluntary. For example, a person can choose to document their decisions on the



AHD form, other ACP document (for example, Statement of Choices (SoC)) or in another manner, such as a letter.⁷⁵ While ACP should be encouraged, this step should not be forced; in particular, many people with close family relationships deliberately choose not to complete formal ACP documents, as there is openly acknowledged agreement within the family unit about what the person would want should they lose decisional capacity. However, the person should be informed that by documenting their preferences in writing they have a greater chance of ensuring their preferences for treatment and care will be followed at a time when they are no longer able to make decisions for themselves.

Advance Health Directives

In Queensland, an AHD (sometimes known as a living will in other countries such as the UK and US), is a formal document in which an adult provides direction about health matters which are to be followed should the person lose capacity. The person may also nominate one or more people to make decisions on their behalf if decisional capacity is lost. There are provisions in both the *Powers of Attorney Act 1998* and the *Guardianship and Administration Act 2000* that set out how AHDs operate generally, and more specifically to address decisions to withhold or withdraw life-sustaining measures.⁷⁶

An AHD activates only when a person loses capacity for decision-making. See [Appendix 8](#) for more information about AHDs and Queensland's legal framework in the context of ACP.

Enduring Power of Attorney

An Enduring Power of Attorney (EPOA) is a formal document used to appoint someone to make financial and personal (includes healthcare) decisions on behalf of a person if they become unable to make their own decisions. 'Enduring' means that the power continues even if the person giving it loses the capacity to make decisions.

Acute Resuscitation Plan

The [Acute Resuscitation Plan \(ARP\)](#) was implemented in Queensland Health facilities in 2009 to replace Not for Resuscitation Orders (NFR orders). The ARP is a medical order designed to provide clinical direction to attending teams in the event of a patient's acute deterioration. The ARP records resuscitation planning outcomes following discussion with the patient or their substitute decision-maker (if the patient lacks capacity), and other members of the multidisciplinary team. The ARP also encourages compliance with guardianship laws that require documentation of the decision-making pathway leading to the withholding and/or withdrawal (stopping and/or not continuing) of life-sustaining measures, such as CPR. The ARP was intended to be used in acute situations and therefore is a short form prominently located in the patient's inpatient record. The ARP is not a legal document like the AHD, so it, of itself, does not provide lawful authority or consent when the time comes for decisions to be made. However, if appropriately completed, the ARP does provide clinical authority for all health professionals to act on the directions on the form in the event of an acute deterioration.

For more detailed information about ARPs and resuscitation planning (a subset of ACP), refer to the [End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients - Guidance for health professionals](#).

Statement of Choices

The SoC form is an ACP document developed in 2013/14 by Metro South Hospital and Health Service that provides an indication of an adult's wishes for care at the end of life. The SoC can guide advance care planning conversations, and like the ARP is not a document contemplated in the guardianship legislation and cannot be relied upon in the same way as an AHD. The SoC also records contact details of the person's substitute decision-maker/s and the existence of completed legally binding documents.

For more information about enduring documents and the legal framework within the ACP context, refer to [Appendix 8](#) – Queensland's legal framework.



Step 5 - Coordinate

Best practice care at the end of life is most appropriately delivered by a multidisciplinary team of health professionals who address a person's individual physical, emotional, psychological, social and spiritual needs. The composition of the team may need to alter to meet a person's individual needs as they change over time. Multidisciplinary care requires that health professionals communicate and collaborate so as to ensure that plans are accessible when needed, both within services and across healthcare settings and sectors.

Specific tasks to improve the coordination of treatment and care within the context of ACP include:

- identifying when a person might need the expertise and support of a specific health discipline (e.g. social workers, aged care providers, spiritual advisors, or cultural representatives) or referral to other specialties
- organising/arranging multidisciplinary and/or family meetings as required
- for persons also receiving treatment as an outpatient or in community settings, ensuring/ arranging:
 - case conferences about the plan of care
 - documentation of ACP discussion outcomes and/or inclusion of completed documents in hospital discharge summaries
- ensuring electronic alerts are in place to notify other health professionals of the existence of any completed formal ACP documents
- encouraging individuals to upload any ACP documents they have completed to [My Health Record](#) via MyGov website.

As a person's condition/prognosis deteriorates:

- consider consultation and/or referral to community care and/or palliative care teams, as appropriate.
- ensure that all participants in care, the patient, family and health workers, understand the goals of care and treatment plans. If necessary and in the event of any conflict or misunderstanding, escalate to senior clinicians or facility management.
- whenever possible, ensure processes are in place to manage or arrange for care in the place of dying and bereavement, including emotional, cultural, spiritual and social support to those closest to the person. Queensland has guidelines to support care in the last days of life: [Care plan for the dying person](#) is a multidisciplinary document for use in acute hospital settings, and the [Residential Aged Care End of Life Care Pathway](#) is for use in residential aged care settings.

Communication examples: when spiritual or existential concerns are raised

- Validate the importance of such topics and encourage the patient to continue to explore the issues with you, or refer where appropriate.
- These are important issues. Consider asking whether the person would like to speak to a member of the hospital support staff such as a pastoral or spiritual caregiver.
- *"... is clearly really important to you. Would it be [useful/helpful] to explore these issues further? Who might be the right person you can talk to about this?"*
- *Would you like to talk to someone about spiritual matters?*
- *What are the things in life that give you strength and sustain you?*
- *Are your beliefs being challenged by your current experiences?*



Step 6 - Review

As previously discussed, ACP is not a single event but an iterative process for plans that evolve over time. This is because as people age, their circumstances change, and/or their health deteriorates, their preferences and decisions about current and future health care may also change. Consequently, ACP should be reviewed regularly to ensure currency, consistency and appropriateness with a person's circumstances, needs, goals and preferences. In particular it is recommended that ACP be reviewed:

- if the person is diagnosed with a life-limiting illness or serious co-morbid medical condition which will greatly impact their prognosis and/or quality of life
- when the person's medical condition or individual circumstances change e.g. diagnosis of new illness, death of a carer/partner, change of substitute decision-maker, change in location of care etc.
- when the person is admitted to hospital for treatment
- if deterioration in the person's medical condition is also associated with significant functional decline
- if new treatment or medical care becomes available, which, for example, changes a person's prognosis, treatment plan and care needs
- if a person with capacity changes their mind about future care or revokes their AHD or EPOA.
 - Note: Individuals with capacity can change or revoke their formal ACP documents at any time. As AHDs or EPOAs are formal documents, this must be done in writing.⁷⁷ Should a person revoke their legal documents, it is a good idea to encourage the person to make others aware of the changes, particularly if it involves changes to potential substitute decision-makers.

Health professionals should also ensure through regular review that:

- all decision-making is in accordance with the standards of good medical practice and is in the person's best interests
- the person's AHD is valid by ensuring that:
 - the directions in the AHD apply to the current circumstances
 - there is a certified copy of the AHD on file together with other appropriate notations about the existence of the AHD – for example, on an ARP
 - the AHD is signed, witnessed and completed where necessary
- all completed ACP documents are checked for currency and consistency.

Careful documentation of the outcomes of discussions is required at all stages of the ACP process. Some of this documentation is required by law, such as recording the consenting pathway if the decisions involve life-sustaining measures, such as CPR.

As ACP is dynamic and non-linear, documents should be reviewed frequently and the responsibility for initiating review clearly identified.



System-wide strategies to embed advance care planning into routine care

The *Statewide strategy for end-of-life care 2015*⁷⁸ (Strategy) recognises the importance of individuals being empowered to undertake ACP, and the pivotal role of all health professionals in supporting the delivery of high-quality care at the end of life. The Strategy provides four key service directions to guide system wide improvement; knowledge, access, quality and safety, and provision. Responsibilities and actions for the Department of Health and HHSs to embed ACP into routine practice and improve care at the end of life across Queensland are identified under each of the four service directions.

To support HHS to embed ACP into routine local practice, the following recommendations are adapted from Scott et al. (2013),⁷⁹ the *Generic care at the end of life implementation plan 2015-2025*,⁸⁰ and the *National Consensus Statement: essential elements for safe and high quality end-of-life care*.⁸¹

Hospitals

- Ensure ACP information is made available to all people on admission.
- Initiate discussions about ACP when:
 - admitting frequently hospitalised patients
 - formulating ARPs or care pathways for chronically ill patients
- Caring for patients transferred from or to residential aged care facilities (RACF).
 - Place clinicians skilled in ACP in all units with sizeable numbers of chronically ill patients (general and geriatric medicine, renal, oncology, cardiac and respiratory); task them with identifying and counselling suitable patients and teaching ACP skills to other staff.
- Document the status of ACP discussions in discharge summaries.
- Utilise discharge co-ordinators to ensure ACP information is communicated to all external clinicians and services including GPs, community and social care providers, residential aged care facilities and external hospice providers.
- Design and implement 'rapid discharge pathways' for patients who are imminently dying or wish to die at home.

Residential aged care facilities

- Routinely initiate ACP discussions between senior nurses, patients and their decision-makers following:
 - admission (ideally this should occur on or very soon after admission)
 - after any major change in clinical status or recent acute hospitalisation, and at yearly intervals, or
 - more frequently depending on deterioration of clinical status, including capacity.
- Make easy to read ACP information available to all new residents, and display promotional material for staff and facility visitors.
- Require facility-affiliated GPs and geriatricians, working with senior nurses, to undertake ACP training and information sessions and implement and audit ACP processes according to best practice.



Outpatient clinics

- Use computer reminders or other follow-up mechanisms to initiate ACP discussions in eligible patients at upcoming appointments.
- Mail introductory ACP material to eligible patients.
- Train nurses or social workers to act as ACP case managers for patients.

Accessibility and standardisation of advance care planning documents

- Require HHS, Primary Health Networks and RACFs to investigate, test and implement area-wide ACP document templates that are standardised, simple, patient-friendly and readily downloadable at the point of care. Ideally, the documentation and resources should work across both the private and public sectors.
- File copies of completed ACP documents in a consistent manner, flag them on all patient records and ensure they can be rapidly retrieved (e.g. via Hospital Based Corporate Information System (HBCIS)).
- Store ACP documents with electronic medical records to enable quick communication regarding changes in plans to all parties involved through shared portals.
- Provide patient-held devices (e.g. bracelets, wallet cards) to flag the existence of ACP documents for the benefit of ambulance services and emergency physicians at times of crisis.
- Provide information about My Health Record and encourage individuals to upload their ACP documents and notify their families and staff that they exist.

Safety and Quality

- Establish appropriate governance structures and arrangements including written procedures about ACP that establish it as a routine component of care. For example, on admission, the status of previous ACP should be checked and recorded, including the existence of or any changes to enduring documents, such as an AHD or EPOA.
- Where possible, include consumers in the design and development of ACP programs and services that support care at the end of life.
- Ensure alignment of ACP programs with systems for recognising and responding to clinical deterioration.
- Establish a person's choices as early as possible via ACP or goals of care assessment
- Implement standardised clinical tools into systems and processes that identify patients nearing the end of life that trigger ACP
- Implement questions regarding ACP into nursing and medical admission assessments.
- Regularly audit ACP processes and document the level of congruence between expressed patient wishes and the care actually received.
- Include a review of the patients last days of life when reviewing deaths in Morbidity and Mortality meetings or case conferences including:⁸²
 - Was there an opportunity to commence end-of-life discussions earlier with the patient, for example, a patient hospitalised more than 3 times in the 12 months prior to dying?
 - Did the patient receive care during or following a clinical review call or rapid response in the 24 hours prior to dying that did not accord with the patient's stated choices?



- Could the treating team have identified that the patient had a severe illness and was at risk of dying during the episode of care despite treatment?
- If appropriate, was there an opportunity for the treating team to commence earlier end of life management planning that included identifying the patient's wishes?
- Implement systems that trigger a review of the person's goals of care, a multidisciplinary case conference and/or family meeting if they are identified as being at increased risk of dying.
- Implement clear care pathways for patients identified as having care needs at the end of life.
- Ensure access to specialist palliative care advice and services.
- Coordinate community and primary care with Aboriginal and Torres Strait Islander health providers to support care planning and service provision within the person's home or place of their choice.
- Coordinate community and primary care with those who specialise in culturally and linguistically diverse communities to support care planning and service provision within the person's home or place of their choice.
- Utilise telehealth models of care to enable readily accessible community-based care.

Professional education and training

- Ensure all clinicians, especially doctors, case managers and social workers, undergo training in ACP and appropriate communication skills relevant to their scope of practice.
- Include innovative techniques in education programs, such as simulation techniques, role-play, scenario analyses and computer-based decision aids.
- Integrate ACP education and training into staff orientation programs.
- Provide education and training on culturally appropriate care at the end of life.
- Utilise telehealth models to deliver education to health professionals in remote HHS sites.
- Clearly promote staff education in ACP to HHS staff, e.g. via HHS Intranet sites
- Include measures of competency in ACP in professional credentialling processes.

Public awareness

- Educate the public in the skills and benefits of ACP and shared decision-making.
- Request HHS media and communications teams to work with clinicians and consumers to implement DoH public awareness campaign.
- Ensure HHS has online information on local ACP services and programs for the community and health professionals.
- Ensure HHS link to Queensland Government franchise and corporate websites for information on ACP.
- Recruit health professionals to sponsor and participate in public engagement campaigns that serve to both educate and prompt patients in discussing ACP.
- Display posters on public noticeboards and provide brochures and texts that introduce ACP in wards, clinics, transit lounges, waiting areas and interview rooms.
- Ensure culturally appropriate ACP information is available for Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse populations.
- Foster staff awareness of ACP using screensaver messages on workstation computers and posters on workstation noticeboards.



Appendices

Appendix 1 – EQuIPNational – advance care planning⁸³

Standard 1 – Governance for Safety and Quality in Health Service Organisations

1.18 Implementing processes to enable partnerships with patients in decisions about their care, including informed consent to treatment

1.18.1 Patients and carers are partners in the planning for their treatment

1.18.4 Patients and carers are supported to document clear advance care directives and/or treatment-limiting orders

Standard 9 – Recognising and Responding to Clinical Deterioration in Acute Health Care

9.8 Ensuring that information about advance care plans and treatment limiting orders is in the patient clinical record, where appropriate

9.8.1 A system is in place for preparing and/or receiving advance care plans in partnership with patients, families and carers

9.8.2 Advance care plans and other treatment-limiting orders are documented in the patient clinical record

Standard 12 – Provision of Care

Criterion 4 The care of dying and deceased consumers / patients is managed with dignity and comfort, and family and carers are supported

Advance Care Planning and treatment limiting orders are included in:

- organisation-wide policies/procedures and systems for end-of-life care
- ongoing professional development for staff.



A multidisciplinary guide to identify those who may benefit from advance care planning (ACP Quick Guide)

Triggers that suggest a person may benefit from advance care planning (ACP):

- 1 The "surprise question" – would you be surprised if the person were to die in the next year?
- 2 The person is experiencing symptoms and signs that indicate declining health
- 3 The person is experiencing indicators of decline related to their specific disease or condition
- 4 The person reaches or experiences a significant milestone e.g. advancing age (i.e. aged ≥65 years or older, or ≥55 years if an Aboriginal or Torres Strait Islander person), retirement, bereavement, admission to community or aged care facility
- 5 The person, family member or carer raises ACP with a health professional

Symptoms and signs of declining health:

- Advancing disease—unstable, deteriorating, complex symptom burden
- Decreasing response to optimal treatments, decreasing reversibility
- Repeated unplanned (emergency) hospital admissions
- General physical decline and often unwell; prolonged recovery periods
- Declining functional performance status (e.g. Palliative Care Outcomes Collaboration (PCOC) indicators (RUG-ADL, SAS and AKPS), reduced mobility, increasing dependence in activities of daily living
- Presence of other risk factors (e.g. social determinants of health – smoking, obesity, diabetes, depression)
- Resident of or about to enter Residential Aged Care Facility
- Presence of an increasing burden of comorbidities (comorbidity is regarded as the biggest predictor of mortality and morbidity)
- Deteriorating physical and mental status following a significant event, e.g. serious fall, retirement on medical grounds
- Choice to discontinue medical treatments and focus on quality of life
- Progressive unplanned unexplained weight loss in last 6 months (>10%) or failure to regain weight lost

Indicators of decline related to specific diseases/ conditions:

Cancer	Heart and peripheral vascular disease	Neurological disease including dementia
<ul style="list-style-type: none"> • Diagnosis of malignancy • Person is becoming less able to manage usual activities and symptoms getting worse • Metastatic disease (spread to other organs) • Persistent symptoms despite optimal therapy • Refer to Cancer Prognosis tools for further information (e.g. PiPs, Pap, PPI, PPS) 	<ul style="list-style-type: none"> • Diagnosis of moderate to severe: <ul style="list-style-type: none"> – atherosclerosis – myocardial infarction – valvular heart disease – cardiomyopathy – lung disease • Frequent ischaemic chest pain • Short of breath when resting, moving or walking a few steps • Increasing heart failure (HF) symptoms despite maximum tolerated HF therapy, including diuretics, ACE inhibitors and beta-blockers • Intractable peripheral oedema • Worsening or irreversible end-organ damage (including cardiac cachexia) • Repeated hospital readmissions with deteriorating HF, ventricular arrhythmias or cardiac arrest • Peripheral ischaemia (claudication) 	<ul style="list-style-type: none"> • Diagnosis of any progressive neurodegenerative disease, e.g. Parkinson's disease, Motor Neurone Disease, Multiple Sclerosis, stroke or dementia. <ul style="list-style-type: none"> – deteriorating physical health or cognitive function – declining mobility or falls – deteriorating speech/communication – progressive dysphagia • Recurrent aspiration pneumonia • Residual paralysis following a stroke • Inability to care for self without assistance • Urinary and faecal incontinence • Poor outcomes in PCOC indicators (e.g. SAS) • Plus any of the following: weight loss, recurrent sepsis, pressure injury or reduced oral intake
Kidney disease	Liver disease	Frailty
<ul style="list-style-type: none"> • Moderate to late stage (3b, 4 or 5) chronic kidney disease (eGFR < 45ml/min) • Kidney failure complicating other life-limiting conditions or treatments • Non-compliance with recommended treatment • Decision to withhold or withdraw dialysis, whether by patient or doctor, and in whatever circumstances 	<ul style="list-style-type: none"> • Deterioration in past year with complications such as: <ul style="list-style-type: none"> – ascites – hepatic encephalopathy – renal impairment – recurrent infections – oesophageal varices – spontaneous bacterial peritonitis • Diagnosis of cirrhosis with one or more complications in the last year, including: diuretic resistant ascites, hepatic encephalopathy, hepatorenal syndrome • Alcohol-related liver disease • Liver transplantation options unlikely 	<ul style="list-style-type: none"> • Multiple co-morbidities with significant impairment in day-to-day activities and: <ul style="list-style-type: none"> – deteriorating functional performance status – combination of at least three of the following symptoms: weakness, slow walking speed, significant weight loss, exhaustion, low physical activity • Decreasing appetite and oral intake • Levels 6-9 using the Clinical Frailty Scale
Lung disease		
<ul style="list-style-type: none"> • Disease assessed to be moderate to severe (e.g. from GOLD II - FEV1 50-79% predicted to GOLD IV - FEV1 <30% of predicted) • Recurrent hospital admissions (≥ 3 in last 12 months due to COPD) • Fulfils criteria for long-term oxygen therapy • MRC dyspnoea scale grade 3-5 (levels of breathlessness after activity) • More than 6 weeks of systemic steroids for COPD in preceding 6 months • Persistent symptoms despite optimal therapy, with surgery becoming more risky. 		

Adapted from: Gold Standards Framework. *Proactive identification Guidance* (FIG) 6th Ed. 2016; University of Edinburgh. *Supportive and Palliative Care Indicators* SPICI tools; Alzassad A. Melhus et al. A tool for prediction of risk of rehospitalisation and mortality in the hospitalised elderly: secondary analysis of clinical trial data. *BMJ Open* 2015;5:e007259. doi:10.1136/bmjopen-2014-007259; Australian Commission on Safety and Quality in Health Care. *Safety and Quality of End-of-Life Care in Acute Hospitals: A Background Paper*. Sydney: ACSQHC, 2013).

Please see reverse for purpose of this guide and recommendations for further steps to carry out ACP



Queensland
Government

Identifying people who will benefit from advance care planning (ACP)

(Purpose of this guide and recommendations for further steps to carry out)

What is the purpose of the ACP Quick Guide?

The purpose of this multidisciplinary ACP Quick Guide is to assist clinicians to identify when a person may benefit from ACP earlier in the course of their illness. It may also assist to identify those who may be approaching the end of life before significant deterioration of their condition occurs.

Why do we need a guide to identify people who may benefit from ACP?

According to the Australian Commission on Safety and Quality in Health Care, “(C)linicians and patients should identify opportunities for proactive and pre-emptive end-of-life care discussions, to increase the likelihood of delivering high-quality end-of-life care aligned with the patient’s values and preferences, and to reduce the need for urgent, after-hours discussions in emergency situations.”¹

National and international research agrees that predicting mortality and the timing of decline can be difficult, even for experienced clinicians. A single page of broad indicators supports health professionals to identify whether the person in their care is approaching the end of their life and the potential for further decline. While it is never too early or too late to commence ACP, evidence is growing that people benefit most from carrying out ACP as early as possible in their disease trajectory. People who are identified as being at risk of deterioration are more likely to participate actively in their current and future treatment and care.

It is most beneficial for patients, their families² and the multidisciplinary healthcare team to commence ACP before the person suffers a loss of capacity and becomes unable to express and/or document their own preferences and choices about end-of-life care. Early identification of those who may benefit from ACP provides opportunities to actively involve the person and those closest to them in their current and future treatment and care.

Who can use the ACP Quick Guide?

Any healthcare professional who is looking for more guidance to identify those who will benefit from ACP can use this guide. While experienced clinicians may be aware of their patient’s declining health, there are times when guidance is needed to make a more holistic assessment of whether the person may benefit from ACP. Caring for patients who are approaching the end of life offers opportunities for the multidisciplinary healthcare team to identify their patient’s needs, coordinate and review their goals and plan of care, and consider how best to align care with their expressed values, goals and wishes.

Documenting decisions and potential decision-makers is also an important part of the ACP process, and the responsibility of all involved in the treatment and care of the person.

What happens when a person is identified by the ACP Quick Guide?

If a person is identified as likely to benefit from ACP, the range of health professionals involved in their care should initiate an appropriate ACP process leading to a multidisciplinary review of their treatment plans. After a more thorough clinical assessment of the person’s condition, ongoing discussion, coordination and review with the multidisciplinary healthcare team can assist the person and their family to prepare for treatment and care when their condition deteriorates (refer to the [ACP Clinical Guidelines](#) or [ACP flip cards](#) for more information).

What happens if a person falls outside the purpose of the ACP Quick Guide?

A person may fall outside the purpose of these guidelines if they are well. It is never too early to undertake ACP and this can occur by following the six steps in the ACP process, as explained in the [ACP Clinical Guidelines](#). Healthy people may decide to engage in ACP and this should be encouraged. Sometimes initiating ACP may be triggered by exposure to literature, posters and conversations that promote ACP in the well community.

Quality of life and comfort for the person and those closest to them will be the focus in the last days and hours of life through palliative care. The [Care plan for the dying person](#) (CPDP) is designed for those patients who are actively dying in the terminal phase of their disease. Most people who are near to dying should have been identified without the need to refer to the ACP Quick Guide; however that does not preclude their engaging in ACP for what may, in reality, be a limited range of choices.

When in doubt, it is best to initiate ACP in the context of a general discussion about the person’s health and well-being. In this way, consent can be obtained and the ACP process followed. No harm can come from initiating ACP early. (Refer to the [ACP Clinical Guidelines](#) or [ACP flip cards](#) for more information, including the ACP process, clinician responsibilities, and legal issues around obtaining and documenting consent).

Where does the ACP Quick Guide fit with other ACP documents?

This guide is Appendix 2 in the [ACP Clinical Guidelines](#) and was developed to support the identification of those at or approaching the end of life, representing step 1 (identify) of the 6 step ACP Process.

1. Australian Commission on Safety and Quality in Health Care. *National Consensus Statement: essential elements for safe and high-quality end-of-life care*. Sydney: ACSQHC, 2015. p. 11.

2. Please note in this ACP Quick Guide the term family is used as the most likely support for the person identified as being at the end of life. Close family members are usually, but not always, substitute decision-maker/s. Where legal consent is required, ensure the person’s decision-maker/s is consulted. Refer to the [ACP Clinical Guidelines](#) for further information.



Appendix 3 – Identifying persons for advance care planning discussions: disease specific clinical indicators

Oncology

Clinical Indicators

- Deteriorating performance status and functional ability due to metastatic cancer, multi-morbidities or not responding to treatment – if spending more than 50% of time in bed/lying down, prognosis estimated in months
- Cancer Prognosis tools available e.g. PiPs, Pap, PPI, PPS
- Also refer to Clinical Prioritisation Criteria resources under [Oncology and Malignant Haematology](#) ([biopsy proven new diagnosis of lymphoma](#), [breast cancer](#), [colorectal cancer](#), [head and neck cancer](#), [lung cancer](#), [Lymphadenopathy for investigation](#), [multiple myeloma](#), [testicular cancer](#)).

Examples of issues to consider

- What is the person's understanding of their cancer and their stage of disease?
- Does the person understand what is meant by primary and secondary/ metastatic cancer?
- Curing the cancer might be more difficult if it has spread to other organs
- Have treatment interventions commenced? (Refer to the [Cancer care statewide service strategy 2014](#) for further details, esp. Clinical Cancer Care Framework, p. 32)
- Does the person know if their treatment is curative or palliative?
- Does the person think it more important to live long or to live well?
- Does the person know they can choose to stop palliative chemotherapy?
- Is the person aware of the support available as their disease progresses?
- How much control does the person want to maintain over what happens to them?
- What is the person's greatest concerns/fears?
- Who can assist/support the person with their decision-making?
- Who will and when can the issue of the terminal phase and person's death be discussed, including their preferred place of dying?
- What are the implications if the person refuses admission to hospital? Should the person be referred to palliative care services?
- Does the person have an ARP? Should the patient have an ARP? Is this an appropriate time to discuss resuscitation planning?
- What is the plan for coordination with other health professionals and services and follow-up of the patient?

Renal disease

Clinical Indicators

- Stage 3 to 5 chronic kidney disease (CKD) with deteriorating health and with at least 2 of the indicators below:
 - person for whom the 'surprise question' applies
 - persons choosing the 'no dialysis' option, discontinuing dialysis or not opting for dialysis if their transplant has failed
 - persons with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
- Other symptoms of renal failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload
- Commencement of dialysis in end stage renal disease (ESRD) with poor functional status
- Failure of multiple vascular access and/or modalities for renal replacement therapy
- Deliberate non-compliance with recommended treatment.



Examples of issues to consider

- Identify persons who would benefit from a palliative approach for their CKD:
 - persons managed conservatively; *i.e.*, a GFR ≤ 15 ml/min per 1.73 m^2 with no dialysis
 - consider using an integrated prognostic model⁸⁴
- Screen for and manage pain and other physical symptoms routinely.
 - a simple tool such as the POS-S (renal) (Palliative care Outcome Scale)
 - the Edmonton Symptom Assessment Scale (ESAS) is also appropriate and has been validated in CKD⁸⁵
- Enhance predialysis education:⁸⁶
 - is the person aware of the stages of kidney failure?
 - provide information regarding conservative care options
 - information should include available palliative care other community services
 - what does the person know about the options for both haemodialysis and peritoneal dialysis?
 - is the person aware of the benefits and burdens of each choice, how will they be managed, and the implications for other treatments they may be receiving?
- Dialysis:
 - does the person know that they can withdraw from dialysis at any time they choose?
 - what action would they want taken should their vascular access fail?
 - what do they understand regarding the outcome when they opt either for not starting or withdrawing from dialysis?
 - has the person been on home therapy that has now failed and does not wish to commence hospital haemodialysis?
- Transplantation:
 - is the person suitable for, or considering, transplantation?
 - is the person's transplant failing and have they stated that they do not wish to return to dialysis treatments?
 - what is the person's understanding of what will happen?
- What are the implications if the person refuses medical treatment for their renal disease? Should the person be referred to palliative care services?
- Does the patient have an ARP? Should the patient have an ARP? Is this an appropriate time to discuss resuscitation planning?
- What is the plan for coordination with other health professionals and services and follow-up of the person?

Respiratory

Clinical Indicators⁸⁷

- The American Thoracic Society (ATS) provides criteria for staging the severity of airflow obstruction (ratio of FEV₁ to forced vital capacity [FEV₁/FVC]) and its severity as measured by % of predicted FEV₁. ATS and the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria for assessing the severity of airflow obstruction (based on % of predicted post-bronchodilator FEV₁ when the FEV₁/FVC is $< 70\%$) are as follows:
 - GOLD I (mild) - FEV₁ 80% or greater of predicted
 - GOLD II (moderate) - FEV₁ 50-79% of predicted
 - GOLD III (severe) - FEV₁ 30-49% of predicted
 - GOLD IV (very severe) - FEV₁ less than 30% of predicted**GOLD combined assessment of COPD incorporates assessment of the severity of airflow obstruction, symptom assessment and history of exacerbations.**⁸⁸
- The Australian and New Zealand guidelines for the management of COPD (COPD-X) were developed by the Thoracic Society of Australia and New Zealand (TSANZ) and Lung Foundation Australia (LFA). The classification of severity of COPD is outlined in the following table:



	MILD	MODERATE	SEVERE
Typical Symptoms	Few symptoms Breathlessness on moderate exertion Recurrent chest infections Little or no effect on daily activities	Increasing dyspnoea Breathlessness walking on level ground Increasing limitation of daily activities Cough and sputum production Infections requiring steroids	Dyspnoea on minimal exertion Daily activities severely curtailed Experiencing regular sputum production Chronic cough
Lung Function	FEV ₁ ≈ 60-80% predicted	FEV ₁ ≈ 40-59% predicted	FEV ₁ ≈ < 40% predicted
FEV ₁ ≈ = forced expiratory volume in one second			
Table adapted from: Lung Foundation Australia's Stepwise Management of Stable COPD available at Lung Foundation Australia (Stepwise Management of Stable COPD)			
<ul style="list-style-type: none"> The 2011 American College of Physicians/American College of Chest Physicians/American Thoracic Society/European Respiratory Society (ACP/ACCP/ATS/ERS) guideline for diagnosis and management of stable COPD indicates a history of more than 40 pack-years of smoking was the best single predictor of airflow obstruction; however, the most helpful information was provided by a combination of the following 3 signs:89 <ul style="list-style-type: none"> Self-reported smoking history of more than 55 pack-years Wheezing on auscultation Self-reported wheezing. Other factors for COPD or other chronic respiratory conditions include: <ul style="list-style-type: none"> Weight loss (Body Mass Index below 18) Respiratory failure (PaCO₂ > 50mmHg) Right sided heart failure Worsening shortness of breath Pulmonary hypertension Fulfils long term oxygen therapy criteria (PaO₂ ≤55 mm Hg on room air) 6 weeks steroids in preceding 6 months requires palliative medication for breathlessness. 			
Examples of issues to consider			
<ul style="list-style-type: none"> Does the person have any co-morbidities associated with their respiratory condition (e.g. Ischaemic Heart Disease (IHD), osteoporosis, anxiety, depression, lung cancer, diabetes, glaucoma and sleep disorders)? Is the person aware of the option for ventilatory support (particularly non-invasive ventilation) on exacerbation of their respiratory condition? What is the person's understanding of their quality of life, future care and treatment options? What type of treatment or care would the person like during acute exacerbations of their COPD or other respiratory condition? Where would the person like to be cared for? (e.g. hospital/community)? Are they aware that there may be options other than hospital admission (e.g. Hospital in the Home (HITH)) Does the person understand the difference between invasive and non-invasive ventilatory support during acute treatment for their condition? What are the person's views on these types of ventilation? If the patient's breathing deteriorated to the point of needing ventilatory support, would they accept this? What are the implications for the person's care if they choose to limit, withhold or withdraw ventilatory support in the future? What are the implications if the person refuses admission to hospital? Should the patient be referred to palliative care? Does the patient have an ARP? Should the patient have an ARP? Is this an appropriate time to discuss resuscitation planning? What is the plan for coordination with other health professionals and services and follow-up of the person? 			



Cardiology

Clinical Indicators

Identifiers of patients with advanced heart failure and poor prognosis:

- Patient with consistent NYHA class IV HF
 - unable to undertake physical activity without discomfort
 - symptoms of chronic HF present at rest
 - severe chronic HF

and

- Not suitable for any further procedures, such as:
 - revascularization with coronary bypass surgery
 - coronary angioplasty
 - valve surgery
 - cardiac resynchronization therapy (biventricular pacing [BiV-P])

plus, at least one of:

- increasing HF symptoms despite maximum tolerated HF therapy, including diuretics, ACE inhibitors and beta-blockers, as indicated
- worsening or irreversible end-organ damage (including cardiac cachexia)
- repeated hospital readmissions with deteriorating HF, ventricular arrhythmias or cardiac arrest
- Extensive, untreatable coronary artery disease with breathlessness or chest pain at rest or on minimal exertion⁹⁰
- Severe, inoperable peripheral vascular disease.

(ACE, angiotensin-converting enzyme; HF, heart failure; NYHA, New York Heart Association)

Examples of issues to consider⁹¹

- Is the person's heart condition improving with treatment? Are there signs of deterioration or other comorbid conditions? (e.g. dyspnoea and fatigue) Which symptoms bother them most?
- Sometimes all available medication/therapy does not make the patient feel better or relieve the symptoms of their heart failure (and other co-morbidities) (e.g. shortness of breath, water retention and fatigue.) What are the person's goals for treatment care at this time and into the future, as their condition deteriorates?
- What is the person's functional status? (e.g. six-minute walk test and NYHA functional class)
- What does the person understand about the progression of chronic heart failure?
- Has there been an assessment of the person's cardiovascular risk factors? (e.g. hypertension, dyslipidaemia, diabetes, smoking and obesity)
- Have other tests been carried out that are appropriate for the person? (e.g. electrocardiogram, echocardiogram, pathology tests - biochemistry and haematology)
- Has an assessment for reversible causes of chronic heart failure been conducted? (e.g. myocardial ischaemia, anaemia).
- Other assessments of the person's condition as they might relate to and affect their heart condition? (e.g. nutritional status, cognitive function, issues associated with ageing and frailty (e.g. risk of falls, vision or hearing impairment, and incontinence)
- Is the person and their family/carers aware of the unpredictability of chronic heart failure and how it may impact on decision-making?
- Has there been an assessment of the person's need for surgical procedures and/or other supportive electronic device implantations? (e.g. implantable cardioverter defibrillators, pacemakers and left-ventricular assist devices). Would the patient accept such a device? What do they understand to be the benefits and burdens of these devices (e.g. the need for removal prior to cremation)? For example, an Implantable Cardioverter Defibrillator (ICD) can be deactivated at the end of life to prevent prolonging the dying process.
- Deactivation of AICD - should be discussed first at the time of implantation.
- Where does the person wish to be treated now and in the event of an acute deterioration?
- Does the patient have an ARP? Should the patient have an ARP? Is this an appropriate time to discuss resuscitation planning?
- What is the plan for coordination with other health professionals and services and follow-up of the person?



Neurological Disease

Clinical Indicators⁹²

- Diagnosis of any progressive neurodegenerative disease (e.g. Parkinson's disease, motor neurone disease, multiple sclerosis)

General indicators:

- Progressive deterioration in physical and/or cognitive function despite optimal therapy
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure.
- Symptoms which are becoming increasingly complex and difficult to control
- Speech problems: increasing difficulty in communications and progressive dysphasia.
- Mobility problems and falls

Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments
- Increasing "off" periods even with the use of complex drug regimes
- Cognitive impairment notably the onset of dementia-
- Weight loss
- Dyskinesias and mobility problems
- Psychiatric symptoms (depression, anxiety, hallucinations, psychosis)

Motor Neurone Disease

- Increasing cognitive difficulties
- Rapid decline in physical status
- Low vital capacity (below 70% predicted spirometry), or initiation of NIV
- Weight loss

Multiple Sclerosis

- Dysphagia + poor nutritional status.
- Communication difficulties e.g., Dysarthria + fatigue.
- Cognitive impairment notably the onset of dementia.

Examples of issues to consider

- What are the person's main fears or concerns (e.g. loss of communication, loss of body control)?
- How can the person optimise their functional independence?
- Where does the person want to live now and in the event of an acute deterioration? What has to be done to address these wishes?
- Is the person aware of available support (e.g. Home Care Packages, HITH programs, NDIS)?
- Carer issues – what will happen if the person's primary carer needs hospitalisation or is no longer able to assist with care?
- How can the person and his or her family plan for this?
- What are the person's views (and those of their family/carers) on parenteral feeding and their understanding of the appropriateness of this therapy for their disease/condition (e.g. nasogastric, PEG/gastrostomy insertion)? Please refer to the Australian and New Zealand Society for Geriatric Medicine [Position Statement 12 – Dysphagia and Aspiration in Older People \(2010\)](#)
- Does the person have any opinions/thoughts on interventions related to treating complications such as pneumonia/ chest infections or urinary tract infections (e.g. using intravenous antibiotics)?
- Does the patient have an ARP? Should the patient have an ARP? Is this an appropriate time to discuss resuscitation planning?
- What is the plan for coordination with other health professionals and services and follow-up of the person?



Frailty, Dementia, Stroke

Clinical Indicators⁹³

General indicators

- Advancing age combined with multiple comorbidities
- Deteriorating functional performance scores (e.g. [ADL](#), [Barthel](#), [Karnofsky](#) - also see range of other dementia assessment scales⁹⁴)
- Evidence of cognitive impairment
- Increasing dependence with activities of daily living (unable to dress, walk or eat without assistance)
- Eating and drinking less
- Swallowing difficulties – aspiration pneumonia, need for modified diet
- Urinary and faecal incontinence
- Communication difficulties; decreasing social interaction
- Recurrent falls, especially injurious e.g. fractured femur, hip
- Recurrent febrile episodes or infections; aspiration pneumonia
- Weakness, weight loss exhaustion
- TUGT – time to stand up from chair, walk 3 m, turn and walk back

Frailty indicators

- Weight loss, exhaustion, weak grip strength, slow walking speed and low physical activity
- Recurrent hospital presentations to emergency departments or admissions to acute settings
- See the [clinical frailty score tool](#)

Examples of issues to consider

- Does the person need someone to assist them on a regular basis? Does the person require long periods of time at home because of their condition?
- ACP discussions should commence at diagnosis of dementia or cognitive impairment
- What are the person's main fears or concerns (e.g. loss of communication, loss of body control)?
- How can the person and his or her family/carers optimise their functional independence?
- Where does the person want to live? What has to be done to address these wishes?
- Is the person aware of available support? (e.g. Home Care Packages, HITH programs, HACC services)
- What will happen if the person's primary carer is hospitalised or is no longer able to assist with care? How can the person plan for this?
- What are the person's views (and those of their family/carers) on parenteral feeding and their understanding of the appropriateness of this therapy for their disease/condition (e.g. nasogastric, PEG/gastrostomy insertion)? Please refer to the Australian and New Zealand Society for Geriatric Medicine [Position Statement 12 – Dysphagia and Aspiration in Older People \(2010\)](#)
- Does the person have any opinions/thoughts on interventions related to treating complications such as pneumonia/ chest infections or urinary tract infections (e.g. using intravenous antibiotics)
- Does the patient have an ARP? Should the patient have an ARP? Is this an appropriate time to discuss resuscitation planning?
- What is the plan for coordination with other health professionals and services and follow-up of the person?

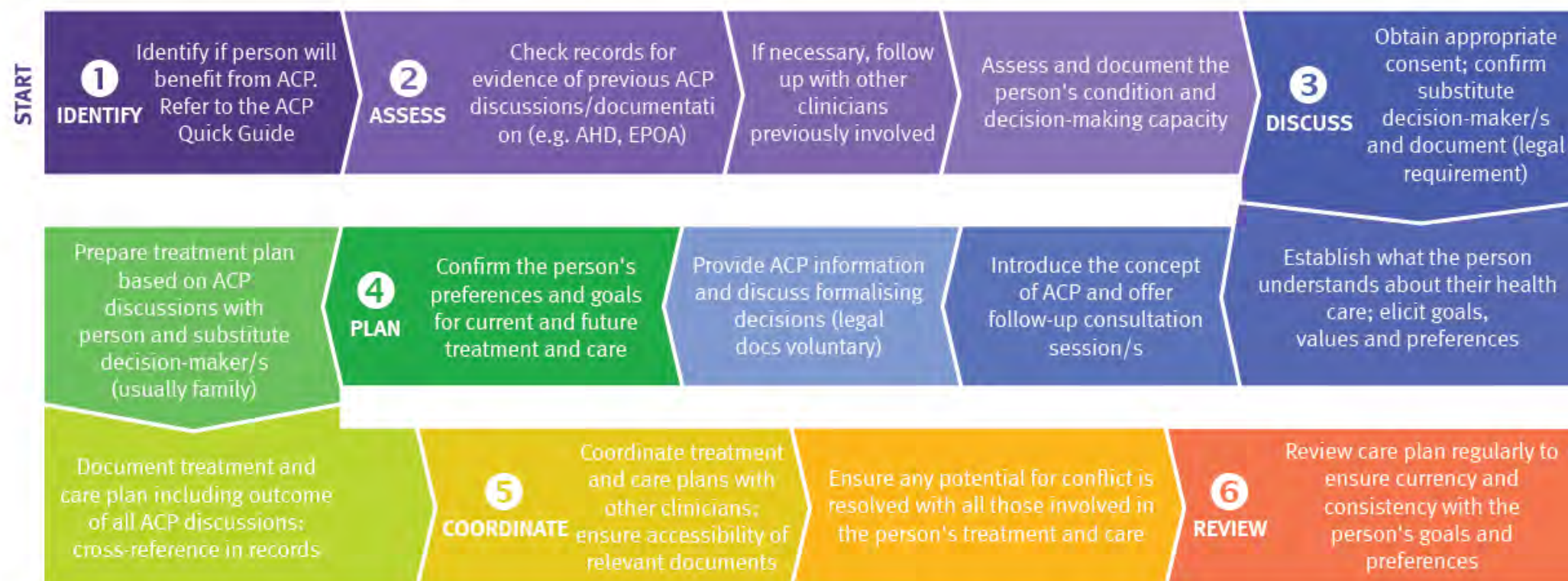


6 Step Advance Care Planning Process

Advance care planning (ACP) is a person-centred approach for planning current and future health and personal care that reflects the person's values, beliefs and preferences. The process of ACP is collaborative and coordinated. It aims to develop an understanding of the person's treatment and care goals in order to assist health professionals to better meet their needs.

Effective ACP involves ongoing communication between the person, those closest to them, and a multidisciplinary healthcare team to optimise the person's current treatment, care, and quality of life. ACP can be carried out at any time and will be driven by the person's care needs and their willingness to participate.

ACP is an iterative process and should be integrated into clinical practice and routine care. ACP plans should be reviewed regularly to ensure plans remain consistent with the person's values, beliefs and preferences for health and personal care.



ACP is an iterative process and can commence at any stage. Repeat stages as required. Carefully document to ensure all clinicians can access.

Please note:

This resource is designed primarily for health professionals treating and caring for those at or approaching the end of life.

More information about the 6 step ACP process can be found in the *ACP Clinical Guidelines*, or at <https://www.health.qld.gov.au/careatendoflife>



6 Step Advance Care Planning Process - Considerations

ACP can include:

- assessing the person's current condition and likely prognosis
- establishing the person's health and personal goals, values and preferences
- discussing current and future treatment and personal care options
- identifying the person's decision-makers for a time when they might lack capacity
- documenting treatment and care plans and ensuring they are appropriately communicated and available when needed
- assisting the person to formally document their wishes if they choose to do so
- coordinating treatment and care to reflect the person's goals, values and preferences.

1

IDENTIFY



- Identify those who are most likely to benefit from ACP. Key groups broadly recognised as benefitting most include those: for whom the "surprise question" applies (i.e. would you be surprised if the person were to die in 12 months?), experiencing symptoms and signs of declining health, reaching or experiencing life's milestones (e.g. advancing age, retirement, bereavement)
- Check for general indicators of decline and disease specific indicators related to particular conditions
- Refer to the ACP Quick Guide (Appendix 2 of the [ACP Clinical Guidelines](#))

2

ASSESS



- Check the person's clinical record for evidence of previous ACP discussions/documents - ensure enduring documents (e.g. Advance Health Directive [AHD], Enduring Power of Attorney [EPOA]) are valid (e.g. apply to the current circumstances, up to date)
- Follow up with other clinicians previously involved, particularly if other specialties are involved
- Assess the person's capacity for decision-making - (it is an established legal principle that all adults are presumed to have capacity unless assessed they do not)
- Assess the person's current condition and determine likely prognosis, options and uncertainties for treatment; document
- Consider the need for other decision-makers to be involved if the person has impaired capacity; take any disabilities into consideration

3

DISCUSS



- Obtain the person's consent – this need not be framed as "Will you consent to this discussion?" Rather, expressed as an invitation for the person to talk about their health and personal goals, their experience of illness and what they understand about their current condition; ensure the person remains comfortable to continue the discussion
- Obtain the person's consent to involve others in discussions (part of confidentiality requirements)
- Confirm substitute decision-maker/s and document consenting discussions (part of the legal requirement to document the decision-making pathway)
- Discuss diagnosis, prognosis and realistic treatment options; explain the uncertainties of predicting recovery
- Elicit the person's goals, values and preferences about proposed medical treatment and ongoing care
- Consider/discuss symptom control, pain relief, and other treatment options in the context of changing and deteriorating disease or condition
- Introduce the concept of ACP by describing it without using technical jargon – explain a key step is to identify substitute decision-maker/s in the event of impaired capacity
- If appropriate, introduce resuscitation planning – this is not the sole focus of ACP discussions and should not be forced; be alert for signs of distress
- Provide appropriate ACP information to the person/decision-maker/s – this may include brochures and/or references to ACP websites
- Discuss possibility of person formalising their decisions in legal documents, e.g. EPOA or AHD – ensure people are aware completing legal documents is voluntary
- If the person has impaired capacity, ACP discussions can also be held with their substitute decision-maker/s

4

PLAN



- Ensure open communication is maintained with the person and their substitute decision-maker/s while developing treatment and care plan
- Provide any further information as appropriate, such as for clinical specialty/ community support or other spiritual/cultural support networks
- Based on the person's goals of care and preferences, prepare a care plan that considers current and future treatment and care; build in review mechanisms
- Consider whether the treatment plan provides a realistic balance between active/curative measures and palliative and other support therapies
- Complete appropriate paperwork to support the person's treatment and care plan (e.g. Acute Resuscitation Plan [ARP], Statement of Choices [SoC], Care Plan for the Dying Person [CPDP])
- Ensure treatment and care plan is appropriately documented and communicated to ensure access by multi-disciplinary team

5

COORDINATE



- Involve other teams as appropriate, such as social workers, aged care, spiritual carers, and cultural representatives
- As the person's condition/prognosis deteriorates, coordinate with community care and/or palliative care teams for ongoing support as appropriate
- Any potential for misunderstanding or dispute should be resolved by this stage - involve senior clinicians and/or escalate to facility management
- Ensure processes are in place to manage place of dying and bereavement, including emotional, cultural, spiritual & social support to those closest to the person

6

REVIEW



- Revisit treatment and care goals, and discuss with the person and their family; escalate if any disputes remain unresolved
- Revisit resuscitation planning to ensure earlier decisions about cardiopulmonary resuscitation (for example), reflect person's current goals for treatment and care
- Review previous ACP discussions if, for example: person's circumstances change, hospital admission, unplanned surgery, deterioration in medical condition etc
- Review paperwork to ensure all relevant documents remain valid, current and accessible (e.g. AHD, EPOA, ARP, SoC)



Appendix 5 – Useful scores of functional capacity

Palliative Care Outcomes Collaboration (Functional Assessment in Palliative Care)

- [Resource Utilisation Group – Activities of daily living](#)
- [Symptom Assessment Scale](#)
- [Assessment package](#) (containing protocols, tools and forms)
- Palliative Care Outcomes Collaboration: [Clinical Manual](#) (May 2017)

Karnofsky performance scale index

- a descriptive, ordinal scale that ranges from 100 (good health) to 0 (dead) and emphasizes physical performance and dependency
- Karnofsky index of 70–100 equates to a favourable functional outcome measure
- An [Australia-modified Karnofsky Performance Scale](#) (AKPS) was developed in 2005

Barthel Index (BI)

- measures the capacity to perform 10 basic activities of daily living
- self-care (feeding, grooming, bathing, dressing, bowel and bladder care & toilet use) and mobility (ambulation, transfers and stairs climbing)
- scoring ranges from 0 (totally dependent) to 100 (totally independent)
- BI index score >90: minimal or no disability
- BI index 55-90: moderate disability
- BI index <55: severe disability
- the Royal College of General Practitioners provides a [resource that explains the BI in the context of medical care of older persons in residential aged care facilities](#).

Functional Independence Measure (FIM)

- Reported to be the most widely employed functional assessment tool
- motor domain (13 items)
- cognitive domain (5 items)
- FIM scores: 1 (total assistance) - 7 (complete independence) for each variable
- FIM total score: 18 (complete dependence) - 126 (complete independence)
- ([resource example for rehabilitation after stroke](#))

Functional Status Score for the ICU (FSS-ICU)

- consists of 3 pre-ambulation categories (rolling, supine to sit transfer, and unsupported sitting) and 2 ambulation categories (sit to stand transfers and ambulation)
- Rating: 1 (total dependent assistance) - 7 (complete independence) scale
- Score: 0-35 (0 score: unable to perform a task due to physical limitations or medical status)



Physical Function ICU Test (PFIT)

- used with critically ill patients who may not be able to mobilize away from the bedside, uses four domains
- amount of assistance for sit to stand, rated from 0 (no physical assistance required) to 3 (assistance of 3 people required)
- strength for shoulder flexion and knee extension (rated on the Oxford Muscle Test Scale)
- marching in place (number of steps taken & the time required to complete these steps), and an upper extremity endurance task of arm elevation to 90° shoulder flexion (number of times both upper extremities are lifted above 90° of shoulder flexion)
- [validated](#) in several recent studies

Katz Index of Independence in Activities of Daily Living (ADL)

- commonly referred to as the Katz ADL
- assesses functional status as a measurement of the person's ability to perform activities of daily living independently
- the Katz ADL ranks adequacy of performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding
- scores are yes/no for independence in each of the six functions
- a score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment
- example [resource](#) and [validation](#)

Glasgow Outcome Scale (GOS)

- provides a global assessment of function, often used for traumatic brain injury
- score 1: good recovery
- score 2: moderate disability
- score 3: severe disability
- score 4 vegetative state
- score 5: death
- there is also an [extended version](#) of the GOS

(Please note that none of these scales or indices is specifically endorsed by these guidelines or Queensland Health. Health professionals must exercise clinical judgement in deploying these resources and/or base their use on guidance from senior clinicians, local accepted practice and the clinical circumstances).



Appendix 6 - Special considerations for advance care planning

Children and young people

Children and young people under 18 can participate in ACP; however, they cannot complete formal ACP documents, such as an Advance Health Directive (AHD), EPOA or a will.

Paediatric Advance Care Planning (pACP) provides an opportunity for children and their parents to develop not only a resuscitation plan but broader plans that can include non-medical goals. Such goals or wishes can related to issues such as tissue and organ donation, location of care, spiritual or cultural aspects of care amongst others.⁹⁵

When a child or young person under the age of 18 years does not have capacity to consent to the provision of health care, except in specific situations, consent is obtained from a parent (or other person with parental responsibility).⁹⁶ This includes younger children and those with cognitive impairment (e.g. developmental disability).

To consent to health care, the child or young person must be capable of making their own decisions on what is proposed (forming a sound and reasoned judgment), which shows they are capable of understand the nature, consequences and risks of the treatment. This is often referred to as “Gillick competence” after a legal case in the United Kingdom.⁹⁷ The treatment and care must also be in the child or young person’s best interests. A range of factors relevant to carrying out ACP with children and young people include:

- their level of maturity and intelligence
- whether they understand what the recommended medical treatment is
- why the medical treatment is needed
- what the medical treatment involves
- any risks related to it, such as effects on health, potential complications and also side effects.

In the case of withholding or withdrawing life-sustaining medical treatment, the Queensland Health policy position is that since the matter is so serious even if the child or young person understands the treatment, its consequences and related risks, the young person’s parent or guardian must be involved in the decision-making and provide consent. The doctor must also believe that the decision about refusing treatment is in the child’s or young person’s best interests.

Research has found that adolescents and young adults living with a life-threatening illness want to be able to choose and record:^{98, 99}

- the person they would like to make decisions for them when they can’t
- the kind of medical treatment they want and do not want
- how they would like to be care for
- how comfortable thy want to be
- how they would like people to treat them
- information for their family and friends to know
- how they would like to be remembered.



In cases where there is disagreement between the child or young person, their parents/guardian and the doctor about current or future treatment, a court may need to decide what will happen. The court must consider what is in best interests of the child or young person when making its decision. This is a rare occurrence and usually all attempts are made to reach consensus before having to take a case to the court. For further information about consent for children and young people, refer to Queensland Health's [Guide to informed decision-making in health care](#).¹⁰⁰

General principles and key legal cases involving children and end-of-life decision-making are also presented on the [End of Life Law in Australia website](#).

A Pediatric Acute Resuscitation Plan (PARP) is available, together with guidelines about the withholding and withdrawing of life-sustaining measures for those under 18 years of age.¹⁰¹ Guidelines for ACP and children and young people are under development. It would be beneficial to harmonise the approach across states in Australia. The documents "Voicing My Choices" (for Adolescents) and "My Wishes" (for children) is an established tool used in the United States and can be found on the [Aging with Dignity website](#).

The University of New South Wales is currently undertaking research on "Voicing My Choices: in the Australian context."¹⁰²

The Royal Children's Hospital and Department of Human Services Victoria have recently published an online resource "[Thinking Ahead](#)" which includes a policy paper, framework and discussion guide. These resources will be helpful and can apply to Queensland.

Aboriginal and Torres Strait Islander people

On average, Aboriginal and Torres Strait Islander people die significantly younger than the wider Australian community and have much higher rates of poor health outcomes. Aboriginal and Torres Strait Islander people have the lowest life expectancy of any minority in a first world country.¹⁰³ According to the most recent *Closing the Gap Report*, while there have been decreases in some chronic diseases for Aboriginal and Torres Strait Islander people, they experience higher death rates than non-Indigenous Australians, and the target to close the gap in life expectancy by 2031 is not on track based on data since the 2006 baseline.¹⁰⁴ Certain chronic diseases and conditions make much larger contributions to Indigenous mortality than is the case for non-Indigenous Australians.¹⁰⁵

Aboriginal and Torres Strait Islander peoples are not a homogenous group. Like many cultures, Indigenous Australians comprise a large number of very diverse, culturally different communities. Each community has its own unique customs, cultural beliefs and associated ceremonies. Although there are degrees to which Aboriginal and Torres Strait Islander people are connected through their traditions, the concept of community and the central place of land and family obligations are common underpinning values within and across Aboriginal and Torres Strait Islander communities throughout Australia. Family extends to distant relations, with obligations and responsibilities to all members and others within the community. 'Family' members may not be related according to the mainstream notion of blood relatives, but be related through traditional kinship or cultural groupings. This results in significant differences between non-Indigenous and Indigenous Australians' perspectives on healthcare, wellbeing, death and dying. A common contrast in perspective is the meaning of a hospital admission.¹⁰⁶

- For non-Indigenous people the hospital is a place to heal, to fix health problems, and to rehabilitate.
- For Aboriginal and Torres Strait Islander people, the hospital may be seen as a place one goes to die.



Having to move from isolated communities to regional or metropolitan centres for treatment or care can result in significant social consequences and trauma, not only for the Aboriginal and Torres Strait Islander person, but also for their families. Flexible models of health care for those at the end of life allow Aboriginal and Torres Strait Islander people the choice to return to their place of birth if it is their wish to do so. Care that could make Aboriginal and Torres Strait Islander people more comfortable may be less of a priority than the cultural and family support needed for spiritual wellbeing. Many Aboriginal and Torres Strait Islander people use the 'classificatory system of kinship.' This is a strong relationship-based kinship system inherited by collective groups that provides the social structuring of family and the community (language group, nation or clan).¹⁰⁷ The ceremonies and rituals established over tens of thousands of years are designed to strengthen these family, community and Country connections. "Country" is a term used to describe connection to land, sea and waters as well as ecology, family, spirit, and community/other clans.

If Aboriginal and Torres Strait Islander people feel their cultural and spiritual needs are purposefully not being met during vulnerable times such as end of life, they may not feel safe and comfortable to access health services and delay accessing the hospital and health services, not access services at all, or become display negative behaviour such as verbal aggression. In discussions about end of life matters, information given to Aboriginal and Torres Strait Islander people and/or their family/community should include the range of choices available to them. Knowing the choices and positives/negatives of the choices will assist the Aboriginal and Torres Strait Islander person and/or their family/community to:¹⁰⁸

- make an informed decision about what is best for them – even if it means not accessing available services
- plan for time away from home
- plan for family members to accompany the person
- prepare for what is likely to happen in relation to the illness.

Understanding and demonstrating respect for the beliefs of the person and their family will assist with developing trust and rapport.¹⁰⁹ Queensland Health endeavours to support cultural practices and beliefs of Aboriginal and Torres Strait Islander people throughout the illness that results in their death, and afterwards. Queensland Health has developed specific guidelines to assist health professionals and services to deliver appropriate, culturally competent care at the end of life for Indigenous Australians.¹¹⁰ The Australian Government's National Palliative Care Program also provides important resources to discuss end of life matters with Aboriginal and Torres Strait Islander people.¹¹¹

To find an Aboriginal and Torres Strait Islander health service that can support ACP in your area, check the Queensland Aboriginal and Islander Health Commission ([QAIHC website](#)). QAIHC is the peak body representing the Community Controlled Health Sector in Queensland at both a state and national level. Its membership comprises of Community Controlled Health Services (CCHS) located throughout Queensland. Nationally, QAIHC represents the Community Controlled Health Sector through its affiliation and membership on the board of the National Aboriginal Community Controlled Health Organisation (NACCHO).

People from culturally and linguistically diverse backgrounds

The Queensland Government Statistician's Office has reported that Queensland's average annual growth rate over the 10 years to 30 June 2015 was 2.0 per cent above the Australian average of 1.7 per cent, and that migration has had a major role in this growth.¹¹² There is continuing growth in cultural diversity across Queensland, including a notable growth in South East Queensland. Queensland is an increasingly multicultural society being home to people who speak more than 220 languages, hold more than 100 religious beliefs and come from more than 220 countries.¹¹³



Migration data from the Queensland Government Statistician's Office also produces regular overseas migration figures for Queensland.¹¹⁴ People from other cultures arrive in Australia for a variety of reasons.¹¹⁵ Mostly the decision to relocate is voluntary, but sometimes it is not. Once living in Australia, people who are displaced from their birth country tend to live in the same vicinity to retain their traditional community support. It is to this community support network that people often turn to if they are faced with difficult end-of-life decision-making.¹¹⁶ Migration from the country of birth cuts off many support systems and reduces the recognition and celebration of symbolic events. This can increase the sense of alienation and helplessness at times where difficult decisions are required.

Culture can be defined in many ways; broadly, such as 'the way of life, especially the general customs and beliefs, of a particular group of people at a particular time',¹¹⁷ or more narrowly, such as 'a complex, learned, shared system of human behaviour, rituals and symbolism'.¹¹⁸ Despite the difference between cultures, each has rituals and mechanisms for dealing with death and there are usually common interests that may serve as starting points for the ACP discussion. In most culturally and linguistically diverse groups, the family has traditionally been the main source of security, assisted by adherence to religious or spiritual beliefs.

Generally, many cultural groups approach religion and spirituality very seriously, which may be particularly sensitive to end of life decisions. A number of religions cross language and cultural boundaries, so it is important when discussing ACP with a person to not assume anything, and to understand where religion fits within the spectrum of their decision-making. For example, there may be some for whom religion in the context of their life in Australia does not have as significant a role as it may have in their homeland. However, when faced with a life-limiting illness and the imminent death of a family member or friend, religious practices, rituals and beliefs may resume their importance.¹¹⁹

It is important for health professionals and others to acquire some knowledge about these issues to ensure a sensitive approach when discussing ACP with people from culturally and linguistically diverse backgrounds. Cultural factors shape a person's preferences around decision-making for care at the end of life, particularly when dealing with bad news. The developed world's emphasis on a person's autonomy, informed consent and truth telling is often at odds with the beliefs and values of some cultural groups, who may place greater value on family involvement in decision making as opposed to individual autonomy. For example, in some cultures, discussing death is actively discouraged as it is viewed as an indication of disrespect, likely to extinguish hope, invite death, and/or cause distress, depression and anxiety.¹²⁰ Therefore, significant differences in approaches to death and dying can be observed across the various culturally and linguistically diverse groups in our community. This means that health professionals treating and caring for those who identify with another culture must be mindful about how ACP can be introduced sensitively.

People with a lived experience of mental illness

It is recognised that people do not necessarily lack capacity simply because they live with mental illness. The capacity to make health care decisions is assumed for all adults under law, and disputes about capacity would need to be resolved through clinical assessment. Therefore, mental health issues do not always prevent someone from actively participating in ACP. For example, while a person with an episodic mental health condition has capacity, they may complete an AHD to ensure their wishes for health care are carried out during periods of temporary loss of capacity.

Queensland Health has developed a policy *Advance Health Directives and 'Less Restrictive Way' of Treatment*.¹²¹ This Policy outlines the relevant provisions of the *Mental Health Act 2016* in relation to AHDs and treating persons in a less restrictive way. Promoting the use of AHDs and other alternatives to treatment without consent under the *Mental Health Act 2016* gives individuals greater control over their future healthcare and supports consumer empowerment and patient recovery.



A public brochure that explains AHDs and mental health is available online or through local mental health services.¹²² A detailed guideline and alternate Advance Health Directive Form that applies under the *Mental Health Act 2016* is also available.¹²³

People with disabilities

Under the law, everyone is presumed to have capacity unless it is established by a formal assessment that they do not. Therefore, people with disabilities should not be presumed to lack capacity for participating in and making current and future health care decisions.

ACP for people with disabilities is not a one size-fits-all approach; some people with disabilities may be unable to participate, but others may choose to take an active or partial role. Many people with disabilities will have capacity that allows them to make and act on their own decisions, and they should be encouraged to participate in ACP discussions to the full extent that their abilities allow. There are situations, particularly where people have a cognitive disability, complex support needs and/or communication difficulties, where they may need more assistance to carry out ACP. When a person with disabilities reaches the end of their life, all decision-making must incorporate an underlying respect for their autonomy and ensure all decision-making is in their best interests. Increasingly, the emphasis is upon health professionals to be skilled in supporting people to make their own decisions as far as possible, irrespective of their level of capacity. Recently, the concept of shared decision-making is gathering momentum nationally and internationally. Shared decision-making involves the integration of a patient's values, goals and concerns with the best available evidence about benefits, risks and uncertainties of treatment, in order to achieve appropriate health care decisions. Shared decision-making models are supported by the Australian Commission on Safety and Quality in Health Care (refer to their [webpage](#) on shared decision-making for further information).¹²⁴

For the disabled person who lacks decisional capacity, when the time comes for end of life decisions, particularly about withholding or withdrawing life-sustaining measures, consent will be required from their substitute decision-maker/s, who could be an attorney, statutory health attorney or guardian formally appointed by the Queensland Civil and Administrative Tribunal. Queensland's legal framework is such that there is always someone to represent the interests of an adult who lacks capacity, or who has never had capacity. If there is no-one else available, the Public Guardian acts as the decision-maker of last resort. (For more information, refer to the section below on identifying [substitute decision-makers](#).)

Lesbian, gay, bisexual, transgender and intersex people

According to some researchers, there is little understanding in Australia of the special issues faced by many lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ) people at the end of life.¹²⁵ While many of the experiences of LGBTIQ people in receiving end of life care are similar to those of non-LGBTIQ people, some particular challenges facing LGBTIQ people in accessing care at the end of life are identified in prior literature:

At the end of their lives, GLBT Australians face the possibility of discrimination and inappropriate care. Advance care planning can help mitigate discrimination, particularly in ensuring that same-sex partners and other members of 'families of choice' are involved in end of life care and decision making. As in the wider population, however, significant barriers to advance care planning exist. How GLBT people experience these barriers may reflect their unique experiences and community history, as well as the additional pressure of dealing with services that fail to properly acknowledge gender and sexual diversity.¹²⁶



Many LGBTIQ people experience stigma, discrimination, social exclusion and isolation. At the end of life, these barriers to community participation and engagement may prevent LGBTIQ people from accessing medical, physical, social, psychological, emotional and spiritual care when required, leading to poorer health outcomes. Although the Statutory Health Attorney provisions in Queensland should already ensure that decisions can be made by same sex partners if required, ACP can help mitigate discrimination and ensure certainty, particularly in ensuring that same-sex partners and other family members are involved in decision-making, if that is the person's choice.

For people with capacity, this can be formalised by appointing a substitute decision-maker through an EPOA, or by completing an AHD.

Queensland Health is committed to ensuring care at the end of life for all LGBTIQ people with life-limiting conditions is accessible, inclusive and affirms their right to dignity, respect and confidentiality. Support for LGBTIQ people can be affirmed by involving the person in the ACP process, including their partners, carers, family members of choice, and significant others, if that is what the person wishes.



Appendix 7– Roles and responsibilities for health professionals during the ACP process

ACP is key to achieving high-quality care at the end of life and should be regarded as part of the role of all healthcare professionals. The team involved in ACP and end-of life care for a patient and their family, either through direct decision-making or in supportive roles, may include medical specialists, surgeons, general practitioners, nurses and allied health workers such as social workers, patient advocates and spiritual or pastoral care workers.

There are considerable benefits to be gained by integrating the skills of the multidisciplinary team in the ACP process. A multidisciplinary team approach to ACP can:

- allow staff to contribute their valuable perspectives to the process of planning care
- allow staff to contribute information about treatments and interventions based on their area of expertise
- break the task into manageable components
- provide a sounding board for problem solving complex issues and checking appropriate communication approaches
- ensure staff are working within their areas of competency in translating wishes and values expressed into well-communicated clinical treatment plans.

While all clinicians can carry out many of the components of ACP, there are some that specific health disciplines are better equipped to lead. It is also recognised that individual health professionals will have different degrees of competency, experience and confidence in carrying out ACP that may be independent of their discipline. Therefore as a general rule, health professionals should always operate within their scope of practice and seek the advice and support of multidisciplinary team members as required. Junior nurses and doctors should not be excluded where end-of-life decisions are considered, although they should be supervised in any discussions about end of life decisions with patients or their families.

Reaching agreement within the treating team about appropriate care is an important initial step in a collaborative approach, particularly where the patient no longer has decision-making capacity. It can help reduce subjectivity or bias, particularly in cases of uncertainty. If healthcare professionals are to be encouraged to discuss prognosis and end of life issues with people who have advanced life-limiting illnesses, it is also important to acknowledge the need for support and self-care. Such support includes debriefing with colleagues, encouraging the development of strong collaborative team relationships, and communication skills training.¹²⁷

Doctors

Doctors have a number of vital roles that are key to the successful initiation and implementation of ACP. First and foremost they must lead and promote open conversations about dying, death and individual choice that are a prerequisite for effective ACP. The vital role that doctors play in assisting the community to deal with the reality of death underscores one of the most important objectives of effective ACP.

Specific roles and responsibilities for Doctors include:

- knowing when life-prolongation is not possible and ensuring that patients continue to receive appropriate care and symptom management



- ensuring ongoing support for patients and their families as they make important decisions together about options for treatment and care of the patient at the end of life
- translating decisions made about current and future treatment into a plan for ongoing medical management
- ensuring that treatment and care incorporates the patient's wishes, values and choices, irrespective of their capacity to make decisions about health and personal matters.

Facilitating ACP also allows doctors to introduce the concept of patients formalising their decisions in a written document. This can be achieved by providing appropriate information about ACP and allowing patients to time to absorb the information and have discussions with their families/friends and carers, if available. Doctors should also ensure that when patients have completed ACP documents that they are reviewed regularly, and the most current versions form part of the patient's records and are accessible. In keeping with the doctor's coordination role the existence of completed ACP documents must also be communicated to other members of the patient's multidisciplinary healthcare team.

Senior doctors also have a clear leadership role within the multidisciplinary team to provide advice and evaluate the overall impact of the treatment plan and goals of care on prognosis and wellbeing. In particular, doctors need be involved whenever decisions potentially involve life-sustaining measures. Some people have very strong views about this and doctors must also accept and support those who refuse medical treatment, even if they believe the patient's choices are inconsistent with the standards of good medical practice.

In fulfilling these roles doctors have a duty to ensure they have the skills necessary to communicate important information about ACP effectively with their patients and their families. They must also have a working knowledge of the laws that govern ACP as well as the documents that are used in Queensland to facilitate written recording ACP. The [*Code of Conduct for Doctors: Good Medical Practice*](#) developed by the Medical Board of Australia, describes guiding principles for doctors to initiate and facilitate ACP with their patients in the context of optimum care at the end of life.

Nursing professionals

Research and clinical practice demonstrates that nurses have multiple roles in ACP.^{128,129} These include preparing people to think about end-of-life decision-making for themselves and their family members, providing health professional and public education about end-of-life decision-making, and raising discussions about a person's end-of-life wishes with other members of the healthcare team. Nurses are also ideally placed to monitor how treatment and care comply with patients' preferences, and to facilitate discussions amongst family members.¹³⁰

Because of their close connection with patients and family members and their philosophical commitment to patient autonomy, nursing professionals can take a proactive role in promoting the importance of ACP. Nurses can play specific roles in ACP such as communication facilitator, risk identifier, emotional supporter, advocate, healthcare agenda setter, educator and researcher.¹³¹ One important role performed by nurses within the context of ACP is serving as a patient advocate, ensuring that patients and families receive culturally sensitive care and sufficient pain management and relief of other symptoms.¹³² This role also extends to providing emotional support to the patient and their family. Nurses are also ideally placed to coordinate linkages between the patient and their family with community care and other support agencies.



Allied health professionals

Allied health professionals form part of a multidisciplinary team and have key roles in facilitating ACP. Allied health professionals include: social workers, occupational therapists and physiotherapists, psychologists, paramedics, pharmacists, dietitians, speech pathologists, Aboriginal and/or Torres Strait Islander Health Workers. The roles of some allied health professionals within the context of ACP are briefly described below.

Aboriginal and Torres Strait Islander Health Workers and Liaison Officers

Aboriginal and Torres Strait Islander Health Workers represent a key linkage between the healthcare team and the patient and their family. Health workers can be found in Aboriginal and Torres Strait Islander community health services throughout Queensland. If a patient is transferred from a remote community, the health worker from that community will be the best contact to assist with communication with the patient and their family. Assistance can be sought from Aboriginal and Torres Strait Islander Hospital Liaison Officers within each HHS, or search for the contact details of the community health service in the community that the patient is from. It should be confirmed with Aboriginal and Torres Strait Islander patients in transit where they are from, as sometimes a patient is transferred multiple times, and the medical notes may not reflect this. Aboriginal and Torres Strait Islander health workers can also assist with explaining any cultural expectations on behalf of the patient, contacting family support for the patient, clarifying the patient's medical or family history, or dietary requirements, and providing advice on discharge planning i.e. what services are available to the patient in the community.¹³³

Aboriginal and Torres Strait Islander Hospital Liaison Officers can be found in major Queensland Health hospitals. They provide emotional, social and cultural support and assistance to Aboriginal and Torres Strait Islander inpatients and their families. The liaison officer should be contacted on admission, and their advice should be sought when planning care for the patient during their stay and on discharge. They will be able to determine the cultural appropriateness of care and provide a vital medium between the health care team, the patient and their family. Liaison officers can play an extremely important role when caring for a patient who is dying, or has passed.

Dietitians

Dietitians take into account the patient's current disease context, treatment plans and overall quality of life when developing nutritional plans and education for the patient and those who support them. Within the ACP context, dietitians assist patients to optimise nutritional intake and work with other health professionals to include nutritional plans as an element of the patient's overall treatment.

Occupational therapists

Impairment of physical function and loss of independence significantly contribute to a decreased quality of life. Occupational therapy assists individuals to participate in essential everyday activities in acknowledgement of progressive deterioration. While occupational therapists are integral to a broader ACP process, they may not participate in all aspects of the ACP process for all patients. For those patients who require occupational therapy, the continual readjustment of the goals of care to take account of the patient's functional decline should be integrated into the broader treatment and care planning steps of the ACP process.

Paramedics

A holistic approach to patient care is integral to contemporary palliative care practice and has recently been identified as a key issue in paramedic education.¹³⁴ Increasingly, patients at the end of life,



particularly those receiving palliative care services, are being recognised as an emerging client base for paramedics and other emergency care providers. Paramedics will usually be the first responders for palliative care patients if they are being cared for, for example in the family home, especially in situations of carer distress, sudden deterioration and imminent death, as well as in non-emergent situations such as inter-facility transfers. In each of these scenarios, clinical decisions regarding patient care initiated by paramedics may set the trajectory for subsequent care.¹³⁵ Queensland Ambulance Service has an information brochure about paramedics and palliative care,¹³⁶ and also general guidelines about resuscitation, in particular withholding or withdrawing CPR.¹³⁷

Physiotherapists

Physiotherapists assist in improving a patient's quality of life by maximizing their functional independence and helping to provide relief from distressing symptoms such as breathlessness and fatigue. Physiotherapists can provide valuable care planning information to the broader ACP context, particularly around optimising physical activity and comfort as a patient's condition deteriorates.

Psychologists

Anxiety, depression and complex grief are often seen as key psychological markers for care at the end of life. Psychologists can play an important role in ACP by providing expert psychological assessments and interventions to effectively address psychological issues around life-limiting illness and functional decline. Psychologists can also bring important skills to the ACP context by providing psychological therapy for patients and their families, consultation, supervision and staff support, as well as education and research around end-of-life issues, such as bereavement.

Social workers

Social Workers consider each person's unique situation and their ACP needs by engaging in a systematic process of assessment. Social Workers incorporate the cognitive, emotional and spiritual representations the patient makes of his or her illness as well as their social and service context. This ensures ACP is person-centred and that the process, as well as the plan, is respectful and helpful to patients.

Social Workers use their specialist knowledge of grief, loss and bereavement to assess readiness for ACP discussions. Counselling and psychoeducation skills assist the patient to anticipate and discuss future health states and treatment options.

Social workers, as members of the treating team navigate complex social systems and provide guidance on guardianship and capacity for decision-making. They navigate patients and their families through the challenging task of accessing and understanding legal documents such as the enduring power of attorney. Social workers have important linkage roles (such as discharge planning), case management (for care coordination), and referral to external care providers.

Social Workers are rights-based and advocate for patient autonomy and independence. They seek to avoid crisis decision making that may not be consistent with patient goals.

Social workers are often part of a specialist palliative care teams or may work alongside other health professionals in the community to ensure continuity of help for people needing long term care and support.

Speech pathologists

Speech pathologists contribute to the overall quality of life of patients nearing the end of life and play a key role in many palliative care teams. In the context of ACP, speech pathologists are not usually required until the patient experiences functional decline. Generally, for patients at or nearing the end of



life the goals of speech therapy interventions are to facilitate quality of life rather than being restorative. When patients have difficulty speaking, speech therapists work with the multidisciplinary health team to develop alternative communication strategies that allow the patient to express their needs effectively. An important component of care at the end of life is quality of life and speech pathologists work with patients who have difficulty swallowing to develop compensatory strategies that enable the patient to eat orally for as long as possible. Speech pathologists should have a good understanding the process of dying to understand the emotional and psychological issues faced by their patients during ACP discussions.

Specialist palliative care

Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of individuals with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources. Specialist palliative care services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary health care services.

Within the context of ACP, specialist palliative care is characterised by coordinating and integrating person-centred care in order to promote quality of life for people with life-limiting conditions and their families. It involves assessing need, promoting and advocating for a person's choice, predicting likely problems and planning for the future in the context of a changing and deteriorating disease trajectory. Specialist palliative care services ensures that multiple disciplines and agencies can be accessed and referred to as required in a timely manner. People with life-limiting conditions should be helped to engage with care planning to the extent that they are able to and wish to be involved. The concerns of families and carers should be taken into account as part of this process.

The role of palliative care specialists in the ACP process can include any number of the following core competencies. The ability to:¹³⁸

- recognise the impact of a life-limiting condition on the person and her/his family and be able to provide support in order to help the individual to adapt to the changes in her/his condition
- recognise the impact of a life-limiting condition on the person and her/his family's mental health and coping mechanisms and be able to provide support in order to help the individual to adapt to the bereavement and loss
- appreciate the roles, responsibilities and professional boundaries of individual members of the interdisciplinary team
- understand the collaborative relationship between the person with life-limiting conditions, the health care professional, the family and all the other agents of care involved with the person and the family in order to develop an individualised and coherent plan of care to assist the person and the family to attain realistic goals and outcomes in all care settings
- collaborate effectively with others as a member or leader of a multidisciplinary team
- be able to identify priorities or concerns for the individual with a life-limiting condition and their carers, taking account of the individual's coping strategies and how the person perceives their diagnosis
- in the context of professional scope of practice be able to critically evaluate outcomes of interventions against established standards and guidelines
- demonstrate an understanding of advance care planning and an appreciation of the appropriate time(s) to engage in discussions about preferences for care with the person with a life-limiting condition and her/his family
- Demonstrate an ability to communicate sensitively and clearly about advance care planning with the person, the family and the range of professionals and agencies involved.



Role of non-clinicians in supporting advance care planning

Bereavement counsellors

Bereavement and grief counselling focuses on helping people to understand their grief and to adjust to life after the loss of a loved one. It can also assist people to understand that those touched by the loss may express their grief in different ways. Bereavement and grief is experienced in the context of a person's 'whole being', including their physical, emotional, cognitive, behavioural and spiritual manifestations. When grief is complicated and prolonged, evidence suggests that early intervention is both indicated and effective. Bereavement and grief counsellors can coordinate appropriate local support services. Bereavement support standards are also available for further advice in this area.¹³⁹

Pastoral care workers

Pastoral care workers form part of most palliative care teams and have expertise to discuss spiritual issues. Differences are identified in the literature between pastoral care workers and spiritual advisors. Spiritual care is the umbrella term that describes the basic spiritual support that anyone can provide to help someone deal with his or her spiritual journey in order to experience wholeness and wellness. Pastoral care is the giving of spiritual guidance by a clergy member/leader of a faith group that holds to a specific religious worldview. Pastoral care is provided by someone who has had some theological education and pastoral experience and is often the faith leader for a particular faith group. This type of spiritual support is usually provided by and for those who share similar beliefs and practices. In the context of ACP, pastoral care may be requested by some patients and their families as they may prefer someone to counsel them who adhere to their specific faith.

Spiritual advisors

Spiritual care is considered a basic tenet of care at the end of life. The provision of continual end-of-life spiritual care is the responsibility of the entire ACP multidisciplinary team. In order to meet the various spiritual needs of both patients and their families, it is essential for spiritual advisors to provide information about local support services. This should be multidimensional, reflecting the various formats available. Within the context of ACP, across the healthcare continuum, the cultural and religious diversity of patients and their families is significant. Therefore it is important for spiritual advisors to develop a nuanced knowledge of the beliefs and behaviours of the populations served by their team.

Volunteers

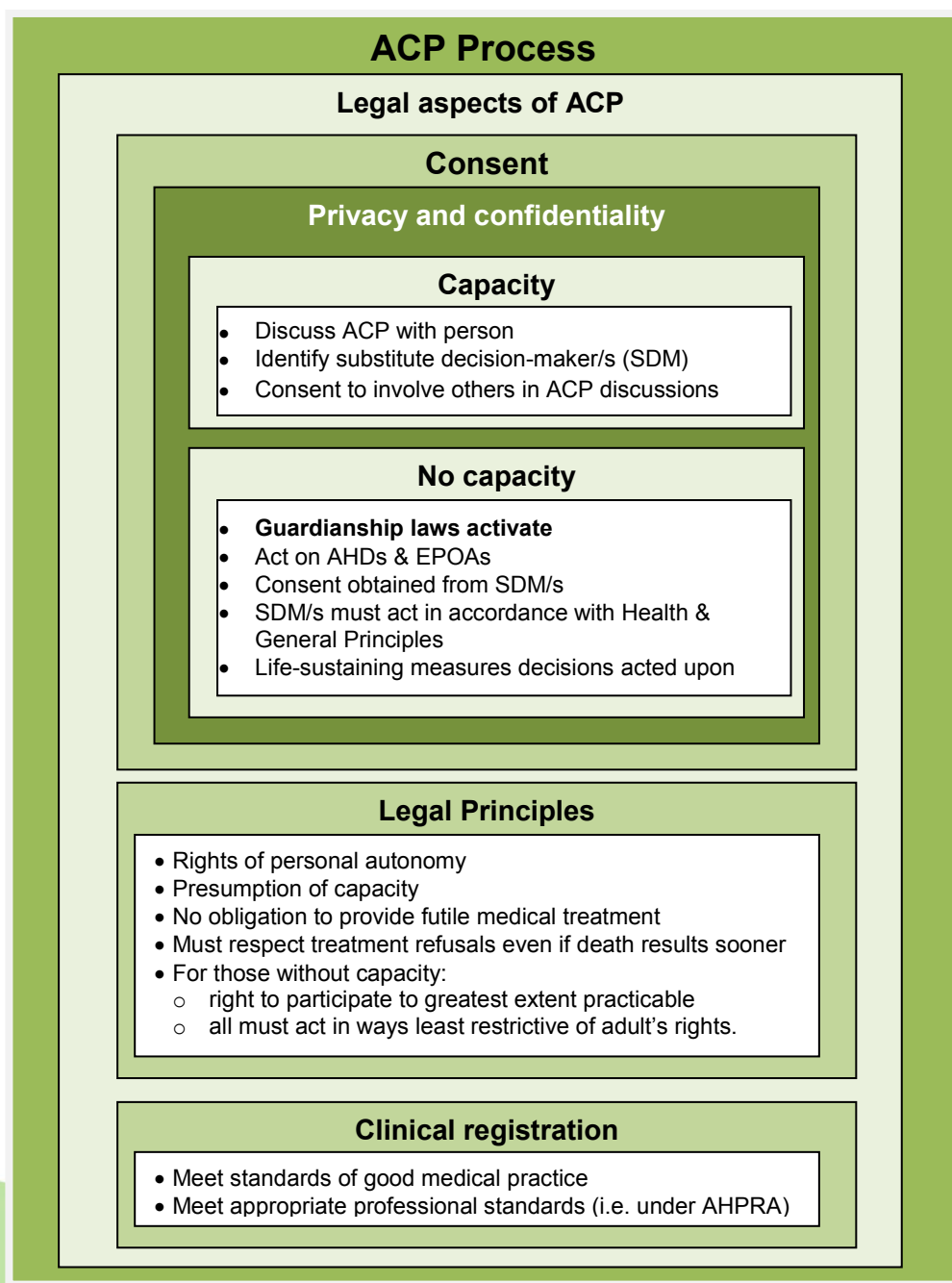
Volunteers are widely used by healthcare teams across many care settings. A number of studies suggest that volunteers can make a substantial contribution to meet the needs of patients and their families at the end of life by providing emotional support, companionship and friendship to patients in end-of-life care.^{140 141} Potential volunteers should be given a clear outline of the role to support patients nearing the end of life as well as their families or friends. Potential volunteers must be appropriately screened and receive suitable training before taking on such a sensitive role. Volunteers should also be supported to help them cope with the demands of the role. To maximise the benefits of volunteer services, it is vital that members of the healthcare team know they exist, understand their role and be able to access them. A useful role description for volunteers was published online in 2016.¹⁴²



Appendix 8 – Queensland’s legal framework

ACP is a broad patient-centred approach that occurs over time that assists people to plan for and decide about current and future care, while upholding their rights and protections under the various laws. While ‘advance care planning’ as a term is not specifically referred to in Queensland’s legislation, there are essentially two legal domains which govern the spectrum of the ACP process:

1. While the person has capacity for decision-making – discussions and decision-making must involve them, reflecting confidentiality and privacy obligations under the relevant laws;¹⁴³ and
2. When the person loses capacity for decision-making – the guardianship laws in Queensland activate,¹⁴⁴ protecting the rights of the person when implementing and acting on decisions made while they had capacity. Note that privacy and confidentiality also applies.



The diagram to the left explains this further. There are three general legal requirements that apply to ACP: consent, legal principles such as patient autonomy, and clinical registration.

Irrespective of the person’s capacity for decision-making, discussing and making decisions about current and future treatment, and then implementing decisions all fall within the ACP process. Privacy and confidentiality provisions will apply whether or not the person has decisional capacity.

For the most part, ACP discussions with a competent person are just like any other discussion involving health matters. Laws relating to privacy and confidentiality and the requirement to appropriately document the conversations apply. The legal issues become more complex when the person loses capacity for decision-making and directions made about life-sustaining measures acted upon.



Consent

Consent to engage in advance care planning discussions

Consistent with both ethical and legal principles, personal autonomy means that it is the competent person's choice as to whether they decide to consent to health care.¹⁴⁵ ACP discussions fit broadly within the legal definition of health care, as they involve conversations around diagnosis and overall planning for current and future treatment and care.¹⁴⁶ Therefore, consent will be required to engage the person and/or their decision-maker in the ACP process, observing the relevant privacy and confidentiality obligations.¹⁴⁷ Consent in this sense, is not a contractual "offer-acceptance" transaction, but obtained in general terms when initiating the discussion and checking in throughout the ACP process to ensure the person and/or their decision-makers remain willing to be engaged. Consent in general terms means that the person agrees through their actions, their compliance with the health professional's recommendations, and broadly indicates through the discussions that they wish to participate in the ACP process.

While ACP should be sensitively encouraged, people must not be coerced or forced into ACP discussions. In particular, completing formal documents, like an AHD, is an entirely voluntary process. If the person is not willing to engage in the ACP process or complete formal documents for any reason, this should be respected and discussion attempts deferred to another more appropriate time. If the person continues to firmly reject being involved in the ACP process, it is still possible for health professionals to take steps in the ACP process, for example, by accessing information from the person's records to identify the person's substitute decision-maker in the event the person loses capacity. (Refer to the section below on [substitute decision-makers](#) for more information).

Exercising a fundamental human right, the person while they have capacity can also refuse medical treatment even if this results in their death or would cause it to happen sooner. In exercising this right, the person does not need to be informed about the consequences of their decision to refuse medical treatment in advance, or for others to agree. While the person has capacity, doctors must follow these directions or face the potential for criminal charge of assault or civil action for battery.¹⁴⁸ Note that this differs slightly from the need to establish 'informed consent' to *provide* medical treatment. Equally, when completing an AHD, the person does not have to receive any information about the treatment they are requesting or refusing in the document, however the doctor certifying the AHD must be satisfied that the person understands the nature and likely effect of the health care described in the AHD. Once the person loses capacity for decision-making however, the guardianship laws activate and will govern how the directions made in the person's AHD are to be applied (see section below – [Consent to implement ACP decisions](#)).

ACP can also be carried out on behalf of persons without capacity, or who have never had capacity. Such discussions must occur with the consent of the person's substitute decision-maker, where a plan for current and future health and care can be discussed with them, implemented and reviewed over time. For more information, refer to [Appendix 6](#) about considerations for [people with disabilities](#).

It is important to note that Queensland law does not require consent to health care to be in writing and in many cases, consent can be verbal or simply implied. In the event of a dispute about whether a patient had given valid informed consent, appropriately specific and detailed information documented in the patient's clinical record, provides the best evidence of the communication process followed to obtain the patient's consent.¹⁴⁹

For more information about consent, refer to Queensland Health's *Guide to informed decision-making in health care*.¹⁵⁰



Consent to implement (act on) advance care planning decisions

Implementing the person's decisions, whether formal or informal, made during the ACP process is usually straight forward – essentially, it involves obtaining the appropriate consent to put the person's ACP decisions into practice. Generally, if the person has participated in an effective ACP process, irrespective of how their directions are expressed, their decisions can usually be followed with minimal prospect of legal issues clouding the decision-making process. While the person has decisional capacity, their consent is required to implement or act on decisions that have occurred during the ACP process, including advance treatment refusals. When the person loses capacity for decision-making, legal elements of ACP fall squarely within Queensland's guardianship legislation, which comprises the *Guardianship and Administration Act 2000* and *Powers of Attorney Act 1998*. The mechanisms in the guardianship legislation for substitute decision-making:

- activates only when a person loses capacity for decision-making - either totally or partially and a decision needs to be made now
- covers matters that uphold, support and protect the rights of a person who lacks decisional capacity, including for financial, personal care, and health care matters
- applies only to adults (other laws apply to children and young people)
- provides a consenting framework for patients with impaired capacity, usually through:
 - an [Advance Health Directive](#)
 - [substitute decision-maker/s](#)
 - Queensland Civil and Administrative Tribunal orders
- identifies the types of health care that where health care is authorised to be provided without consent, for example life-sustaining medical treatment in acute emergency situations.

Many, but not all, advance decisions made during an ACP process concern circumstances around providing or withholding and withdrawing life-sustaining measures. Under Queensland's guardianship legislation, there are more stringent provisions concerning life-sustaining measures, either acting upon the person's prior decisions, or obtaining consent from their substitute decision-maker. For this reason, being able to contact the person's substitute decision-maker, access records of prior ACP discussions, and view the person's formal ACP documents, if they have them, is important when consent is needed to implement (act on) healthcare decisions made by the person during the ACP process. For a person who lacks decisional capacity, the exceptions where health care (including withholding or withdrawing life-sustaining medical treatment) is authorised to be provided without consent include where it is authorised by the Supreme Court and in some [acute emergencies](#).¹⁵¹

The guardianship laws in Queensland were designed to ensure that there is always someone to represent the person who lacks capacity, including the Public Guardian who becomes the statutory health attorney of last resort.

The area of the law that applies a person's ACP decisions at a time when capacity is lost can be exceptionally complex and challenging, but this is not always the case. Where valid AHDs are in place, the law is reasonably straight forward. Similarly, if a person's advance decisions are understood and communicated to all parties well in advance of acute deterioration, and there is general agreement about the overall treatment plan between the patient's family and the healthcare team, disputes or conflict are considered rare. Generally, sensitive and inclusive ACP discussions with patients and families combined with thorough documentation can reduce medicolegal risks and the potential for disputes.



From an ethical and practical perspective, it is far preferable for the person, those closest them, and the healthcare team to put agreed care and treatment plans into place that accord with the person's values, beliefs and preferences, rather than waiting for a time where crisis decisions are required with little or no understanding of what the person would have wanted.

From a clinical perspective, medical treatment and care that is in the person's best interests and consistent with the standards of good medical practice includes incorporating their values, beliefs and preferences for care at the end of life.

Substitute decision-makers

Under the guardianship legislation, except in some urgent situations, consent is required to provide or withhold or withdraw health care from a person who has lost decisional capacity.¹⁵² Authority to provide health care can be obtained from the following substitute decision-maker/s (**in order**):¹⁵³

1. **The person's valid AHD** – if the AHD contains a directive about the matter. If no relevant AHD then the first person on the following list who is available, willing and able to act.
2. **A guardian or guardians appointed by the Queensland Civil and Administrative Tribunal (QCAT)** – any person over 18 years who is not a paid career or health professional of the person who lacks capacity can be appointed by QCAT. If there is no person available, appropriate or willing, the Public Guardian can be appointed.
3. **An attorney appointed under an AHD or EPOA** – note there can be more than one person.
4. **A statutory health attorney/s** - An adult's statutory health attorney is the first of the following people who is readily available and culturally appropriate:
 - a spouse or partner of the person if the relationship is close and continuing
 - an unpaid carer aged 18 years or over¹⁵⁴
 - a close friend or relation of the person who is 18 years or over and is not a paid carer.
5. **The Public Guardian** - If no one is readily available and culturally appropriate to act as attorney the Public Guardian becomes the person's statutory health attorney of last resort. Refer to the fact sheet published by the Office of the Public Guardian in relation to other powers of statutory attorneys.¹⁵⁵
6. Since the introduction of the guardianship legislation, end-of-life decision-making formalises a more collaborative approach, involving the person's family and those closest to them and members of the healthcare team. The following matters should be considered in relation to the responsibilities of substitute decision-makers:
 - 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 [Appendix 9](#)). Where substitute decision-makers are considered not to be complying with either of these principles, the Public Guardian should be contacted.¹⁵⁶ An example of a substitute decision-maker not complying with these principles includes demanding medical treatment that is not clinically indicated and restricts their rights in some way.
 - A substitute decision-maker should be identified for all people in preparation for a time when decisional capacity is lost. The law in Queensland is that there is always someone to act on a person's behalf should they lose capacity - the Public Guardian being the substitute decision-maker of last resort.



- A substitute decision-maker acts as the person's representative and ideally should be chosen by the person for this role when she or he is able and willing to make such a choice. Usually a person's spouse, close family member or friend serves this role in the absence of a formally designated substitute decision-maker.
- 7. The expectation is that the substitute decision-maker will make health care decisions based upon 'substituted judgment'; that is, by considering what the person would want had she or he had decisional capacity.
- 8. If the substitute decision-maker cannot decide what the person would choose, then the decision should be based upon the best interests of the person, which is defined as "what most people in that condition would want". However, it should be noted that there is currently no hierarchy under Queensland law that applies an order between substituted judgement and best interests. Both will be applied and balanced when making a decision.
- 9. Formal guardianship around decision-making about health matters is rarely necessary. A guardian is appointed by the Tribunal, based upon a legal determination that the person lacks capacity and there is no one readily available or culturally appropriate to be the person's substitute decision-maker. In most cases, guardianship proceedings are initiated when there are major treatment dilemmas, concerns of abuse, or disputes for a person who lacks capacity and there is no one perceived as having the ability, desire or authority to legitimately act on their behalf.
- 10. Guardianship is also occasionally necessary if there are multiple 'appointed' substitute decision-makers who cannot agree on an approach to medical treatment despite mediation by the healthcare team, or if there is suspicion that the substitute decision-maker/s are acting in their own self-interest rather than the best interest of the person for whom they are responsible.

Advance Health Directives

- In Queensland, an AHD is a legally-recognised expression of a person's wishes in relation to future health care decisions and may be used to nominate one or more people to make decisions on their behalf should they lose capacity to do so.
- An AHD can be acted on **only** when the person loses capacity. If they regain capacity, the AHD cannot be acted on and directions must be obtained from the person.
- Most people choose to use the [prescribed AHD form](#) which can be downloaded from the Department of Justice and Attorney General website. However, this form is not mandated. If the formal requirements for an AHD are met under the law,¹⁵⁷ the written document can take any form.
- To be recognised under the Guardianship laws, an AHD must be:
 1. a written document
 2. signed by the adult person (or by an 'eligible signer' on the adult's behalf)
 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
 4. signed and dated by a doctor (not the witness) and certified that the adult appeared to the doctor to have capacity to make the AHD.
- The healthcare team is entitled to check the validity of an AHD and to sight the original or a certified copy of it.
- It is entirely voluntary to complete an AHD, and no one should be forced to do it.



- Valid AHDs take legal precedence over treatment requests or demands made by family members of the person who lacks capacity.
- It is the responsibility of the person making an AHD to make sure the decisions in their document will be drawn to the attention of healthcare professionals when it is needed at a future time.
- Certified copies of the AHD may be held at the hospital where the person is being treated, in the medical records of the person's GP, 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. Some people may also choose to upload their AHD and other ACP documents to My Health Record.
- An AHD should not be relied upon in any of the following circumstances:
 - the document is obviously defective (such as pages missing, not signed, dated or witnessed)
 - there is doubt about the directions themselves (for example, ambiguous terminology such as 'I don't want heroics')
 - the directions are uncertain or inconsistent with the standards of good medical practice
 - the proposed treatment is not the treatment specified in the AHD
 - the circumstances are different from those that have been set out in the advance decision
 - the person withdrew the decision while they still had capacity to do so
 - personal or medical circumstances have changed to the extent that the direction to withhold or withdraw life-sustaining measures is no longer appropriate
 - the person has done something that clearly goes against the advance decision which suggests they have changed their mind (this must be discussed with them).
- It is also important to establish that the person making the AHD was 18 or older when they made their decision and that they had capacity to do so.
- If the AHD is considered not to be valid, the statutory consent process must be followed, that is, using the person's substitute decision-maker/s to make decisions on their behalf.

Common law health directives

While AHDs formalise the statutory approach by documenting health care decisions to apply at a time when a person no longer has capacity for decision-making, informal directives or common law health directives as they are known, are also recognised. However, the legal complexities in this area mean that common law health directives are not legally binding in Queensland, however they may be considered an 'objection' for the purposes of the guardianship legislation.¹⁵⁸

Essentially, a common law health directive is one that does not meet the formal requirements of Queensland's statutory scheme.¹⁵⁹ Any person can create a common law health directive and it can be in any form, such as a letter, recalled conversation or video. It also must be established that the person had capacity at the time the common law directive was completed and that it was not under any form of duress. A common law health directive can still inform the decision-making process in consideration of and balancing all other relevant factors.

The uncertain legal status of common law directives in Queensland also means that doctors and health professionals are under no obligation to follow its directions. Since common law health directives cannot legally be used for consent like a valid AHD, the legal consenting pathway must be followed for a person without capacity, particularly where the decisions involve life-sustaining measures. Caution should be exercised in this area as a person's common law directive may, for example, request CPR be applied in the event of impaired capacity, which could be considered an objection to the withholding or withdrawing of life-sustaining measures under the *Guardianship and Administration Act 2000*. Further information about the uncertain legal status of common law health directives can be found on QUT's [End of Life Law](#) website.



Acute emergency situations

Acute emergency situations are characterised by the need to make decisions urgently to preserve the life and health of the person. As the person's health deteriorates, the goals for ACP can change, taking on a new focus as the person approaches the end of life. This time can be marked by increasing frailty and a decline in health status, but also by potential acute events, necessitating the need for decisions about resuscitation and life-sustaining measures to be implemented. In almost all cases, except for non-controversial healthcare, consent is required to provide or stop providing health care for the person who lacks decisional capacity. The extenuating circumstances where consent is not required only arises in some emergency situations.

There may also be some situations where it would be inappropriate and against the standards of good medical practice to continue to put efforts into obtaining consent while the healthcare team is urgently trying to save the person's life. Generally, where there is time to do so, consent from the person's substitute decision-maker should be obtained, or an AHD completed, as close to the critical event as possible and practicable. Unilateral decision-making to withhold or withdraw life-sustaining measures from a person who lacks capacity without making efforts to obtain the appropriate consent is unlawful. The only document that can be legally used for consent in these situations is the person's valid AHD. It should also be noted that acting on decisions made during the ACP process about withholding or withdrawing artificial nutrition and hydration will *always* require consent. This is because it is considered rare that decisions about these measures will be required in an acute emergency situation, and therefore there is time to obtain consent.

The complexity of Queensland's guardianship legislation is well-known and extensively debated in the literature.¹⁶⁰ The uncertainty in this area is amplified around decisions about life-sustaining measures and obtaining consent, where it is known the person wants attempts to be made to save their life in the event they suffer an acute event, such as a cardiac arrest. In other words, the person objects or is known to have objected to the withholding and withdrawing of life-sustaining measures, preferring the healthcare team to make all efforts to save them by providing life-sustaining measures, such as CPR. In these situations, the legal position is that the health care team must apply life-sustaining measures until consent is obtained from the appropriate substitute decision-maker to cease them.

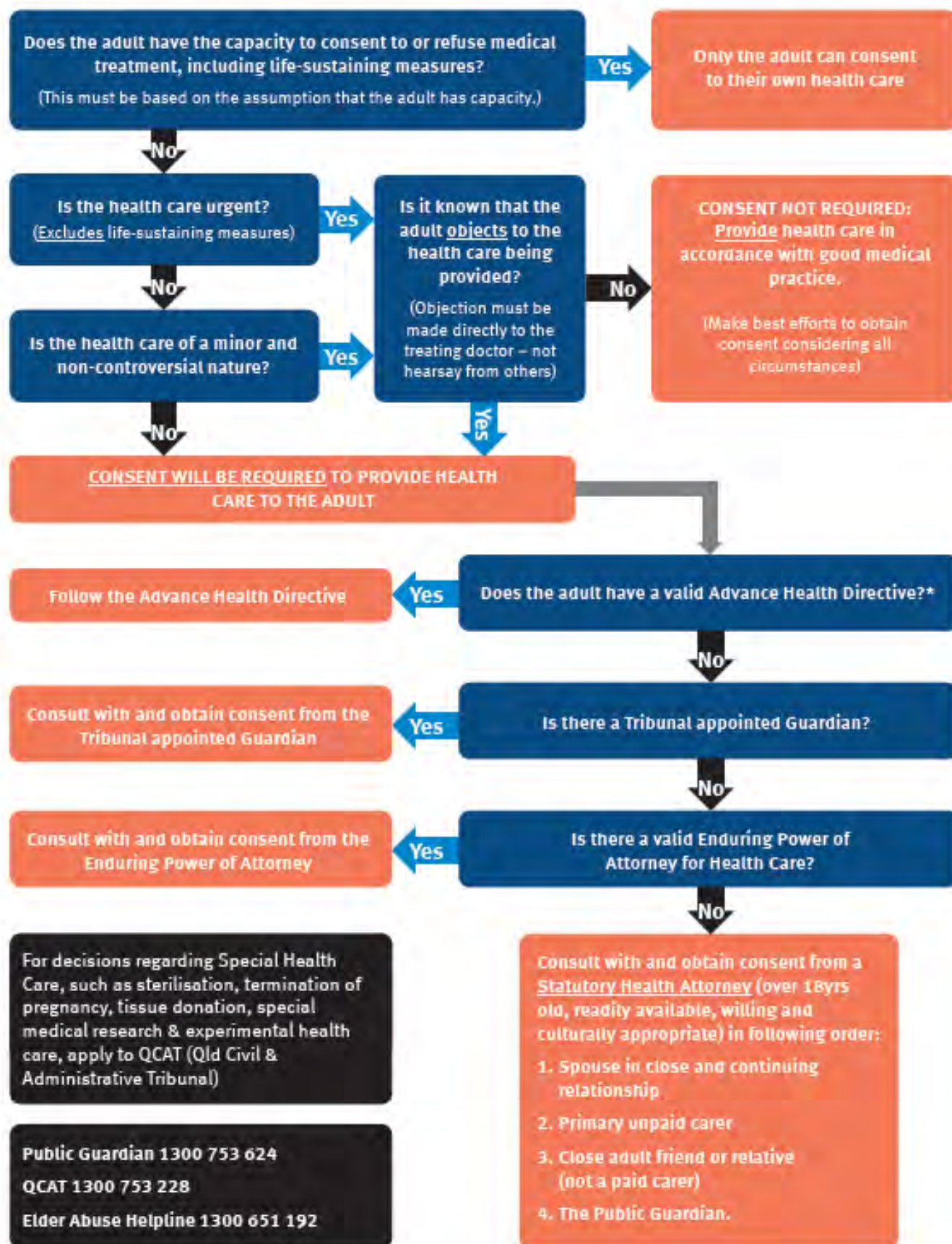
For further discussion of some of the more complex legal, ethical and clinical issues around decision-making about life-sustaining measures and resuscitation planning, refer to the [End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients - Guidance for health professionals](#).

What types of decisions can be made during the ACP process?

During the ACP process there can be many outcomes and decisions relating to the person's financial, personal and health matters that emerge from discussions or are recorded in formal documents – not all of them having direct legal implications for the person or the healthcare team. While the person has capacity, they can participate in ACP discussions and make their own decisions, including current and future treatment and care. When decisional capacity is lost for a particular decision that is required now, the person's substitute decision-maker must apply the general principles for personal matters and the health principle for health matters when making decisions on their behalf (refer to [Appendix 9](#) for these principles). Personal matters may include following the person's wishes for care, place of dying and who is present; observing and carrying out wishes for cultural, spiritual or religious rituals at the time of death. Personal matters under the guardianship legislation also include health care for the person. For certain health matters, such as withholding or withdrawing life-sustaining medical treatment, there are more explicit legal provisions.

The following two pages provide flowcharts to guide obtaining consent in end-of-life decision-making.

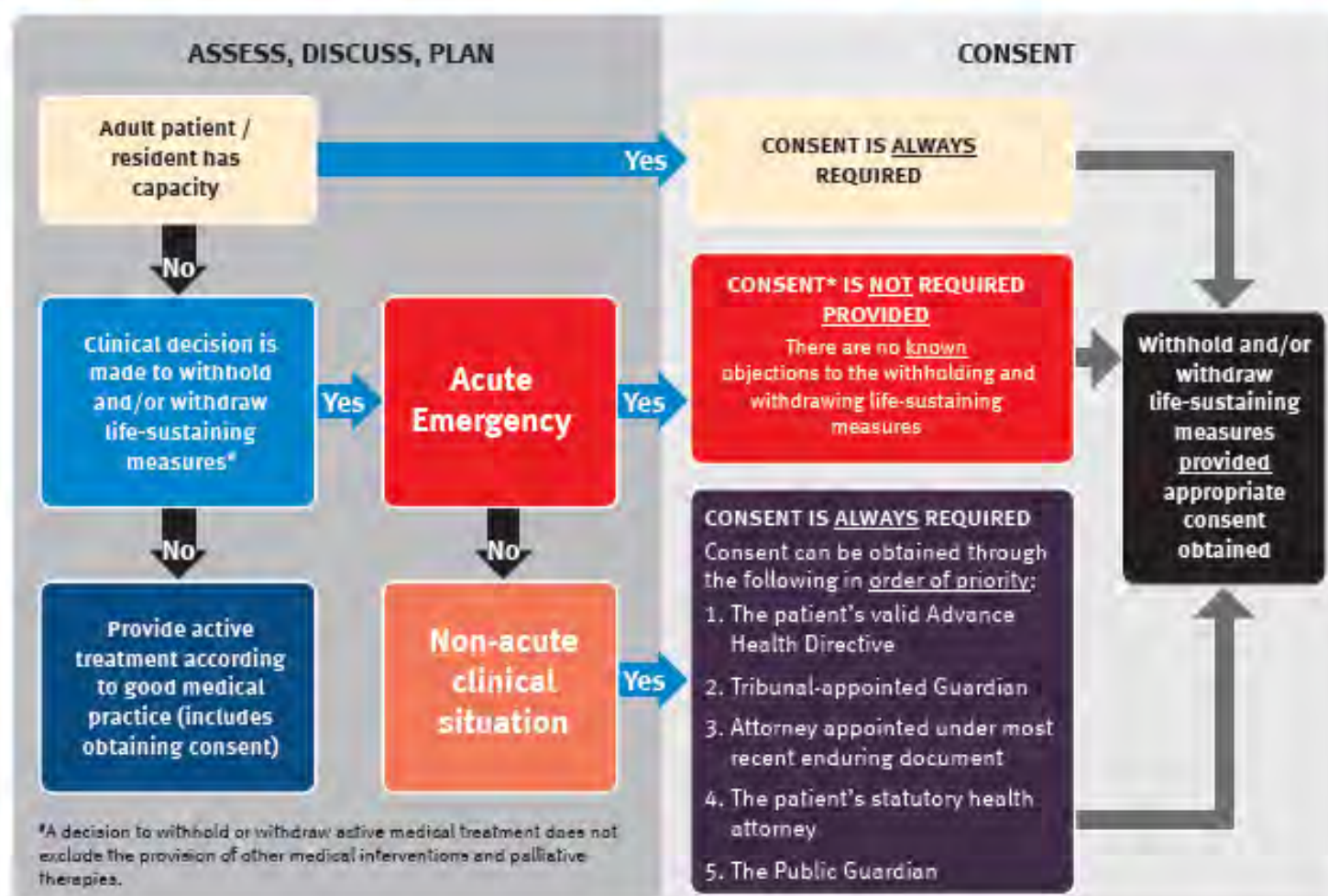
Consent to provide health care to adults



* To be valid, the AHD must be an original or certified copy and apply to the current circumstances. If doubts or uncertainties, consult with the patient's available substitute decision-maker. In these situations, the AHD can still be used to guide the decision-making, but consent will need to be obtained from the appropriate decision-maker. This is particularly important where the adult objects to forms of medical treatment.



Consent to withhold and/or withdraw life-sustaining measures for adults (acute emergency)



*** CONSENT IS ALWAYS REQUIRED IF THE DECISION IS TO WITHHOLD AND/OR WITHDRAW ARTIFICIAL HYDRATION AND/OR NUTRITION IF CONSENT CANNOT BE OBTAINED, OR IF THERE IS A DISPUTE, CONTACT THE PUBLIC GUARDIAN ON 1300 753 624**

Quick facts about consent and life-sustaining measures in acute emergency situations*

- Emergency situations are characterised by the need for an immediate decision to maintain the life and health of a patient. However, 'artificial' emergencies should not be created to avoid obtaining the appropriate consent.
- The law expects health providers to adhere to 'good medical practice' standards. In meeting these standards, doctors are under no obligation to offer, provide or continue treatments that on balance would have the potential to cause harm and offer no benefit to the patient (i.e. futile).
- Consent ≠ 'contract offer + acceptance' (i.e. offer X treatment in order to obtain consent not to provide it). Consent = conversation about the patient's condition, prognosis, goals and overall treatment plan. Ambivalence is not consent. Ensure overall treatment plan is understood.
- In emergency situations, consent is not generally required unless it is known the patient has objected to the withholding and withdrawing of life-sustaining measures (i.e. "wants everything done"). 'Known' = direct knowledge by the doctor in charge, not hearsay from others.
- If the doctor knows the patient with impaired capacity objected to the withholding and/or withdrawing of life-sustaining measures, best efforts to obtain consent from the patient's substitute decision-maker will need to continue.
- All decision-making must be made in accordance with the standards of good medical practice and in the patient's best interests. Good medical practice will also determine the best approach to obtaining consent.
- Medical treatment should never be withheld merely on the grounds that it is easier to withhold treatment than to obtain consent to withdraw treatment which has been commenced.
- Remember: patients with capacity are entitled to refuse medical treatment even if this results in their death or would cause it to happen sooner.
- There is a legal requirement for all decisions about life-sustaining measures to be accurately and thoroughly documented, including recording outcomes of all consenting discussions.
- The statewide Acute Resuscitation Plan (ARP) form was endorsed and implemented in 2010 and specifically designed to document the decision-making pathway for life-sustaining measures in acute emergencies.
- Provided the ARP is appropriately completed, it also provides clinical authority to act upon directions on the form. Note that medical practitioners can be indemnified if this process is followed in good faith. Even if the directions on an ARP are clear, all attending clinicians must also exercise their clinical judgement.

*Please note:

This resource is designed primarily for health professionals treating and caring for those at or approaching the end of life. More detailed information can be found in the *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients* or at <https://www.health.qld.gov.au/careatendoflife>



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Examples of ACP decisions made during the ACP process that are likely have legal implications either under the guardianship legislation or the common law, include the person:

- nominating an attorney, formally or informally (substitute decision-maker – see below)
- making a will
- completing an AHD or EPOA
- creating a “common law” directive, written, oral or in any other way
- refusing medical treatment
- requesting certain medical treatment to be provided when capacity is lost
- nominating who may:
 - be present before and after the person’s death
 - handling of the person’s body after death (for example, if a person is known to have objected to a post mortem, consent will be required to perform one)
 - participate in ACP discussions about health matters
 - participate in ACP discussions about personal care and financial matters.

Examples of ACP decisions made during the ACP process that are not likely to have legal implications beyond adhering to the requisite privacy and confidentiality obligations and appropriate clinical standards, include:

- place of death
- funeral arrangements
- cultural, spiritual or religious rituals to be observed leading up to and after the person’s death.

It should be noted that the concept of ‘informed consent’ differs slightly from consenting provisions under the guardianship legislation around treatment refusals. Informed consent involves the medical information people need to know so they can make decisions, sometimes in advance, about health treatment being provided to them. For treatment refusals, while the person has capacity, they are entitled refuse consent and do not need to be informed, as their decision can be based on any reason, even an irrational one. Moreover, these decisions must be followed even if this causes the person’s death to occur sooner and no one else agrees with their decision. In such circumstances, efforts should be made to provide the information considered required for informed consent and to identify the barriers to the person receiving such information. For further information about consent for health care and informed consent, refer to the [*Guide to Informed Decision-making in Health Care*](#).¹⁶¹

Disputes

Disagreements between the person and his or her family may arise if the family is not properly informed by the healthcare team about the directions given by the person during ACP discussions. Most often this occurs when the patient has lost capacity for decision-making and/or is close to death. More broadly, there is also an inherent conflict between society and its expectations around what modern medicine can potentially offer.¹⁶² Guided by the person’s best interests, every effort should be made to communicate appropriate information to the family, observing privacy and confidentiality legislative requirements.

Disputes can also occur when the person and/or their family misinterpret or disagree with the healthcare team on medical treatment proposed, the person’s prognosis, and whether they believe the medical treatment is in the person’s best interests. Scott et al (2013) point out that most complaints received from bereaved family members about hospital treatment relate to end-of-life care, mainly perceived failures of communication and preparedness for death. Citing a study from 2011, Scott et al (2013) state that doctors spent a median time of only one minute on do-not-resuscitate discussions with patients after acute admission to hospital.¹⁶³



At the end of the ACP process, sometimes families of persons 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 person. More often, a family will ask for 'everything to be done' if they are not ready to accept the person's inevitable death. This situation may be exacerbated when the family is not engaged early in treatment and care planning before the onset of the dying process, or where guilt may be associated with fractured or distant relationships within the family. In such situations, it should be borne in mind that doctors are under no legal or ethical obligation to provide treatment that they believe to be futile, in other words, medical treatment that offers no benefit and could even cause the person harm.

The efforts of the multidisciplinary healthcare team, pastoral care workers, or other spiritual advisors should be directed to supporting family members and helping them to resolve their difficulties when confronted with accepting the reality of the person's impending death. While conflicts are considered relatively rare when an effective ACP process is followed, when they do arise or are likely to occur, senior doctors/consultants should be involved as early as practicable.

In end-of-life disputes, health professionals should be able to demonstrate reasonable justification for their decisions, particularly those which deviate from established clinical guidance. Detailed clinical notes must be kept of any guidelines consulted or additional opinions sought. 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 person and compassion for the family and friends closest to the person. These include the following:

- allow time
- seek a second opinion
- consider a time-limited treatment trial
- convene a family conference
- seek assistance with communication and resolution (for example, from palliative care teams)
- refer the matter to hospital administration or an ethics committee, if this is appropriate.

If consensus cannot be reached or if after mediation attempts, the substitute decision-maker/s refuses to comply with the Health Care Principle (refer to [Appendix 9](#)), the Public Guardian should be consulted to resolve the dispute. However, the Public Guardian can be involved only when the patient has impaired capacity. Clear and thorough documentation of the decision-making process which led to the circumstances, including notes of discussions with family members, will be required in these cases.

For further information about disputes, refer to the [End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients - Guidance for health professionals](#).

Euthanasia and assisted dying

Both euthanasia and assisted suicide are illegal in Queensland, and may result in criminal charges for murder, manslaughter or assisting suicide. At no time during the ACP process should euthanasia or assisted dying be raised other than to sensitively respond that both practices are illegal in Queensland. While there have been many attempts to legalise euthanasia in Australia, apart from the Northern Territory and ACT (since repealed), no States have been successful in decriminalising the practices. If the person or their substitute decision-maker insists on and continues to raise these matters during the ACP process, they must be referred to senior clinicians.

Refer to QUT's [End of life law in Australia website](#), in particular the page about [Euthanasia](#).



Appendix 9 - General Principles and Health Care Principle

General Principles¹⁶⁴

1 Presumption of capacity

An adult is presumed to have capacity for a matter.

2 Same human rights

- (1) The right of all adults to the same basic human rights regardless of a particular adult's capacity must be recognised and taken into account.
- (2) The importance of empowering an adult to exercise the adult's basic human rights must also be recognised and taken into account.

3 Individual value

An adult's right to respect for his or her human worth and dignity as an individual must be recognised and taken into account.

4 Valued role as member of society

- (1) An adult's right to be a valued member of society must be recognised and taken into account.
- (2) Accordingly, the importance of encouraging and supporting an adult to perform social roles valued in society must be taken into account.

5 Participation in community life

The importance of encouraging and supporting an adult to live a life in the general community, and to take part in activities enjoyed by the general community, must be taken into account.

6 Encouragement of self-reliance

The importance of encouraging and supporting an adult to achieve the adult's maximum physical, social, emotional and intellectual potential, and to become as self-reliant as practicable, must be taken into account.

7 Maximum participation, minimal limitations and substituted judgment

- (1) An adult's right to participate, to the greatest extent practicable, in decisions affecting the adult's life, including the development of policies, programs and services for people with impaired capacity for a matter, must be recognised and taken into account.
- (2) Also, the importance of preserving, to the greatest extent practicable, an adult's right to make his or her own decisions must be taken into account.
- (3) So, for example—
 - (a) the adult must be given any necessary support, and access to information, to enable the adult to participate in decisions affecting the adult's life; and
 - (b) to the greatest extent practicable, for exercising power for a matter for the adult, the adult's views and wishes are to be sought and taken into account; and
 - (c) a person or other entity in performing a function or exercising a power under this Act must do so in the way least restrictive of the adult's rights.



- (4) Also, the principle of substituted judgment must be used so that if, from the adult's previous actions, it is reasonably practicable to work out what the adult's views and wishes would be, a person or other entity in performing a function or exercising a power under this Act must take into account what the person or other entity considers would be the adult's views and wishes.
- (5) However, a person or other entity in performing a function or exercising a power under this Act must do so in a way consistent with the adult's proper care and protection.
- (6) Views and wishes may be expressed orally, in writing or in another way, including, for example, by conduct.

8 Maintenance of existing supportive relationships

The importance of maintaining an adult's existing supportive relationships must be taken into account.

9 Maintenance of environment and values

- (1) The importance of maintaining an adult's cultural and linguistic environment, and set of values (including any religious beliefs), must be taken into account.
- (2) For an adult who is a member of an Aboriginal community or a Torres Strait Islander, this means the importance of maintaining the adult's Aboriginal or Torres Strait Islander cultural and linguistic environment, and set of values (including Aboriginal tradition or Island custom), must be taken into account.

Notes—

- 1 **Aboriginal tradition** has the meaning given by the *Acts Interpretation Act 1954*, schedule 1.
- 2 **Island custom** has the meaning given by the *Acts Interpretation Act 1954*, schedule 1.

10 Appropriate to circumstances

Power for a matter should be exercised by a guardian or administrator for an adult in a way that is appropriate to the adult's characteristics and needs.

11 Confidentiality

An adult's right to confidentiality of information about the adult must be recognised and taken into account.



Health Care Principle¹⁶⁵

- (1) The **health care principle** means power for a health matter, or special health matter, for an adult should be exercised by a guardian, the public guardian, the tribunal, or for a matter relating to prescribed special health care, another entity—
 - (a) in the way least restrictive of the adult's rights; and
 - (b) only if the exercise of power—
 - (i) is necessary and appropriate to maintain or promote the adult's health or wellbeing; or
 - (ii) is, in all the circumstances, in the adult's best interests.

Example of exercising power in the way least restrictive of the adult's rights—

If there is a choice between a more or less intrusive way of meeting an identified need, the less intrusive way should be adopted.

- (2) In deciding whether the exercise of a power is appropriate, the guardian, the public guardian, tribunal or other entity must, to the greatest extent practicable—
 - (a) seek the adult's views and wishes and take them into account; and
 - (b) take the information given by the adult's health provider into account.

Note—

See section 76 (Health providers to give information).

- (3) The adult's views and wishes may be expressed—
 - (a) orally; or
 - (b) in writing, for example, in an advance health directive; or
 - (c) in another way, including, for example, by conduct.
- (4) The health care principle does not affect any right an adult has to refuse health care.
- (5) In deciding whether to consent to special health care for an adult, the tribunal or other entity must, to the greatest extent practicable, seek the views of the following person and take them into account—
 - (a) a guardian appointed by the tribunal for the adult;
 - (b) if there is no guardian mentioned in paragraph (a), an attorney for a health matter appointed by the adult;
 - (c) if there is no guardian or attorney mentioned in paragraph (a) or (b), the statutory health attorney for the adult.



Abbreviations

ACP	Advance Care Planning
AHD	Advance Health Directive
ARP	Acute Resuscitation Plan
EOL	End of life
EPOA	Enduring Power of Attorney
GP	General Practitioner
SoC	Statement of Choices



Glossary

Term	Description
Access	<p>Ability to utilise a service or the skills of a suitably qualified person—without difficulty or delay—via a variety of communication mediums. Access may be provided via documented processes with an off-site provider on an inpatient or ambulatory basis.</p> <p>Source: Fundamentals of Framework. Clinical Services Capability Framework for Public and Licenced Private Health Facilities v3.1, Queensland Health.)</p>
Acute Resuscitation Plan (ARP)	<p>An acute resuscitation plan is a medical order which prescribes what treatment will be provided where it can be reasonably expected that a patient might suffer an acute event in hospital in the foreseeable future necessitating the process of resuscitation planning.</p>
Advance Care Planning	<p>ACP is a person-centred approach for planning current and future health and personal care that reflects the person's values, beliefs and preferences. The process of ACP is collaborative and coordinated and aims to understand the person's treatment and care goals in order to assist health professionals to better meet their needs. Effective ACP involves ongoing communication between the person, those closest to them, and a multidisciplinary healthcare team to optimise the person's current treatment and care. When the person becomes too unwell to participate in decision-making, the preparation gained through ACP will guide all those involved in the process to make decisions about health and personal care in their best interests.</p> <p>Anyone can carry out ACP at any time, yet the nature and timing of ACP will often depend on the person's care needs and their willingness to participate.</p> <p>Ideally, ACP discussions should be initiated early for those with life-limiting illness to optimise the person's quality of life and minimise potentially burdensome and unwanted treatment.</p> <p>ACP can include:</p> <ul style="list-style-type: none">• Assessing the person's current condition and likely prognosis• Discussing current and future treatment and personal care options• Establishing the person's health and personal goals, values and preferences• Identifying the person's decision-makers for a time when they lack capacity• Documenting treatment and care plans and ensuring they are appropriately communicated• Assisting the person to formally document their wishes if they choose to do so• Coordinating treatment and care to reflect the person's goals, values and preferences <p>ACP should be integrated into clinical practice and routine care, and reviewed regularly to ensure plans remain consistent with the person's values, beliefs and preferences for health and personal care.</p>



Advance Health Directive (AHD)	<p>An AHD acts as the person's decision-maker should they lose capacity for decision-making about health matters. An AHD also formalises an adult's wishes about current and future health matters and may nominate one or more people to make decisions on their behalf should they become unable to do so.</p> <p>Queensland's AHD is given force under both the Powers of Attorney Act 1998 and the Guardianship and Administration Act 2000. The legal effect of a person's AHD is as if the person gave the directions when they had capacity.</p> <p>There is a prescribed AHD form that can be downloaded from the Department of Justice and Attorney General website. However, this form is not mandatory. Provided the formal requirements for AHDs are followed under the law, 166 the written AHD can take any form.</p>
Artificial hydration and/or nutrition	<p>Artificial nutrition and/o hydration refers specifically to techniques for providing nutrition and/or hydration because the patient is unable to swallow. It includes the use of nasogastric tube, percutaneous endoscopic gastrostomy (PEG feeding) and total parenteral nutrition.</p>
Best interests decision-making	<p>Best interest decision making AHMAC (2011) states that decision making according to best interests should:</p> <ul style="list-style-type: none"> focus on the person's best interests not on what the substitute decision maker would or would not do take into account risks verses benefits and the consequences if not carried out seeks to optimise benefit while minimising restriction.
Care at the end of life	<p>Care at the end of life (or end of life care) is defined as, 'healthcare services aimed at meeting the holistic needs of people (including infants and children) whose life expectancy is anticipated to be shortened as a result of known progressive life-limiting conditions, and where the primary intent of care may have shifted from life prolongation to a focus on quality of life'.</p>
Common law	<p>'Common law', also referred to as case law or precedent, is based on the idea that like cases should be decided alike. Common law develops through judgements of courts on matters brought before them.</p>
Common law directive	<p>Common law directives are those which are governed by the common law (i.e. through courts) and do not meet the requirements of the statutory scheme. There are no formal requirements for common law directives; that is, they can be oral or written, but the person must have decisional capacity and voluntarily make their directive. It should be noted that in Queensland only statutory AHDs are legally binding, that is the AHD (whether or not on the prescribed form) must comply with the relevant parts of the guardianship legislation.¹⁶⁷</p>
End of life	<p>The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is uncertain or unknown. It may be as long as, or longer than, 12 months, as in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.</p> <p>(From the Australian Commission on Safety and Quality in Health Care (May 2015). National Consensus Statement: essential elements for safe and high-quality end-of-life care.</p>
Goals of care	<p>Goals of care identify the aims for a person's medical treatment as agreed between the person, their family, carers and health care team. Goals of care may also include non-medical goals such as returning home or reaching a particular milestone. Establishing goals of care is a very important part of the ACP process.</p> <p>Medical goals of care may include cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying person.</p>



Good Medical Practice	Good medical practice is good medical practice for the medical profession in Australia having regard to - (a) the recognised medical standards, practices and procedures of the medical profession in Australia; and (b) the recognised ethical standards of the medical profession in Australia.
Health care ¹⁶⁸	(1) Health care , of an adult, is care or treatment of, or a service or a procedure for, the adult— (a) to diagnose, maintain, or treat the adult's physical or mental condition; and (b) carried out by, or under the direction or supervision of, a health provider. (2) 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. Health provider Means a person who provides health care, or special health care, in the practice of a profession or the ordinary course of business. Examples are medical officers, dentists, social workers, psychologists, nursing professionals.
Life-sustaining measure	The legislation defines a life-sustaining measure as health care intended to sustain or prolong life that maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation. Life-sustaining measures include, but are not limited to; cardiopulmonary resuscitation, assisted ventilation and artificial nutrition and hydration. Other life-sustaining measures might include; drug therapies, antibiotics and renal and liver failure treatments (e.g. haemodialysis, peritoneal dialysis, hemofiltration). Life-sustaining measures do not include unusual or extraordinary forms of treatment taking into account the available facilities and resources available to provide for the patient's care.
My Health Record	The My Health Record (previously known as the Personally Controlled Electronic Health Record) was launched on 1 July 2012. A My Health Record is a secure online summary of an individual's health information. The My Health Record System Operator is the Secretary of the Department of Health. The individual controls what goes into their My Health Record, and who is allowed to access it. An individual's My Health Record allows them and their doctors, hospitals and other healthcare providers to view and share the individual's health information to provide the best possible care. Further information can be obtained from the My Health Record website.
Non-beneficial treatment	Non-beneficial treatment refers to medical interventions that will not be effective in treating a person's medical condition or improving their quality of life. Non-beneficial treatment may include interventions such as diagnostic tests, medications, the provision of intensive care, and medical or surgical procedures.
Palliative care	Palliative care is an approach that improves the quality of life of persons and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. [Source: World Health Organisation].
Person-centred care	Person-centred care focuses on collaboration between health workers, the person and their carers. Person-centred care is centred on the person and respects their wishes and needs. It is demonstrated by consultation with the person about their healthcare and their active participation in decision-making. Person-centred care is a way of thinking and doing things that sees the people using health and social services as equal partners in planning, developing and monitoring care to make sure it meets their needs. This means putting people and their families at the centre of decisions and seeing them as experts, working alongside professionals to get the best outcome. ¹⁶⁹



Statement of Choices (SoC)	The SoC form is an ACP document, developed in 2013-14 by Metro South Hospital and Health Service that provides an indication of an adult's wishes for care at the end of life. The SoC was designed as a longer-term ACP document to be completed over time, and initiated long before urgent decisions about life-sustaining measures are required. The SoC is not a legal form, therefore cannot be used as the consenting mechanism like an AHD. However, a SoC can be used to guide the ACP process.
Statutory Health Attorney¹⁷⁰	<p>(1) For a health matter, an adult's statutory health attorney is the first, in listed order, of the following people who is readily available and culturally appropriate to exercise power for the matter—</p> <ul style="list-style-type: none"> (a) a spouse of the adult if the relationship between the adult and the spouse is close and continuing; (b) a person who is 18 years or more and who has the care of the adult and is not a paid carer for the adult; (c) 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 for the adult. <p><i>Note</i>— If there is a disagreement about which of 2 or more eligible people should be the statutory health attorney or how the power should be exercised, see the <i>Guardianship and Administration Act 2000</i>, section 42 (Disagreement about health matter).</p> <p>(2) If no-one listed in subsection (1) is readily available and culturally appropriate to exercise power for a matter, the public guardian is the adult's statutory health attorney for the matter.</p> <p>(3) Without limiting who is a person who has the care of the adult, for this section, a person has the care of an adult if the person—</p> <ul style="list-style-type: none"> (a) provides domestic services and support to the adult; or (b) arranges for the adult to be provided with domestic services and support. <p>(4) If an adult resides in an institution (for example, a hospital, nursing home, group home, boarding-house or hostel) at which the adult is cared for by another person, the adult—</p> <ul style="list-style-type: none"> (a) is not, merely because of this fact, to be regarded as being in the care of the other person; and (b) remains in the care of the person in whose care the adult was immediately before residing in the institution.
Surprise question	The use of a 'surprise' question can improve end of life care by identifying individuals or populations with a likely poor prognosis ('would I be surprised if this patient dies in the next year?' or 'how many of my current patients would I not be surprised if they were to die in the next year?'). The 'surprise question' is now widely used and was made popular by the Gold Standards Framework from the UK.
Values	Values refer to a person's principles or standards of behaviour and their judgement of what is important in life.



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