

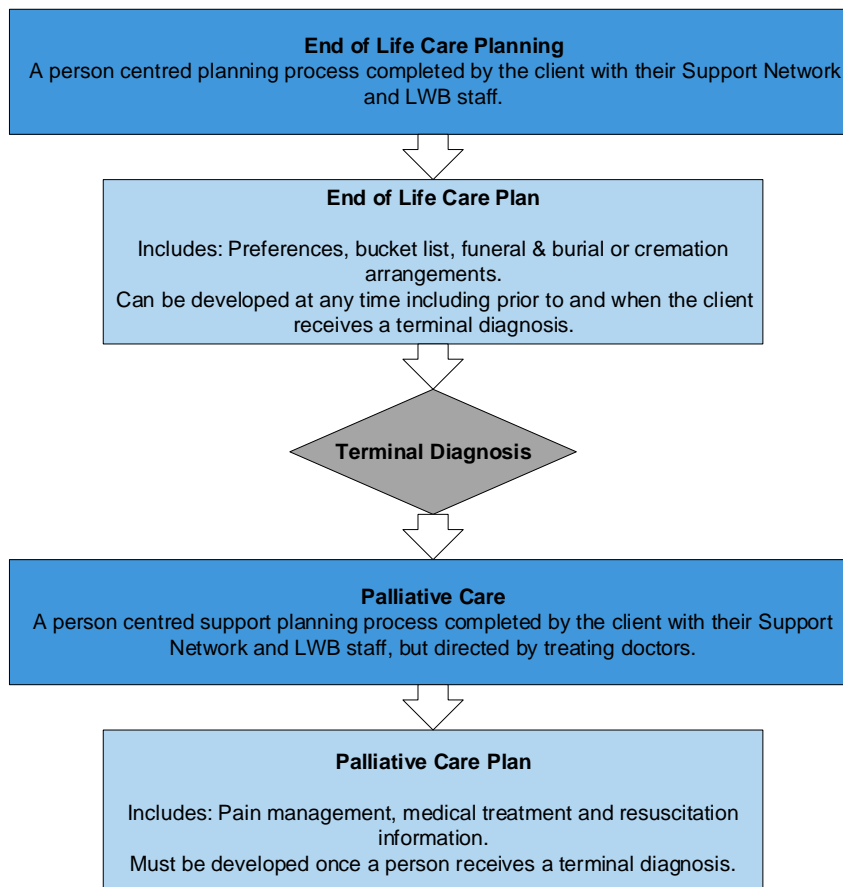
Introduction to End of Life and Palliative Care Planning

Life Without Barriers (LWB) places the people we support, their families and carers at the centre of decision making including when they are undertaking End of Life planning. LWB will ensure that each person accesses the most appropriate supports to meet their end of life' needs, goals and preferences.

At LWB, supporting a person as their life ends follows two approaches:

End of Life Care Planning can be undertaken at any time, as well as after the diagnosis of a terminal condition and addresses the person's preferences for how they want to be supported as their life ends including who they want to see, how they want their surroundings to be, what they want to achieve if possible and how they want their funeral and burial to be carried out.

Palliative Care Planning is the specific care directed by treating doctor(s) that provides specific medical and health related instructions including pain management, dietary and physical support that is to be provided to a person in the final stages of their life. A Palliative Care Plan may also include instructions relating to life sustaining measures such as Cardiopulmonary Resuscitation (CPR) and when to provide or withdraw those measures.



Who should read this document?

LWB staff including Disability Support Workers, nursing staff and Managers who have a responsibility in understanding and or providing support to a person as their life ends.

End of Life Care Planning

End of Life Care Planning is a person-centred process undertaken to assist the person we support and their support network to develop an End of Life Care Plan. The End of Life Care Plan can address the person's environmental, social, emotional and spiritual needs, family support and care of the body after death aligned with the person and their family's preferences.

End of Life Planning can also include creating a "bucket list", maintaining or mending relationships with family and friends, looking at what's working well in life, making changes where needed as well as thinking about anything they no longer want to participate in.

The End of Life Care Plan can also include specific decisions such as where the person we support wants to be located as they die (e.g. home - if possible), funeral arrangements such as music, clothes, venue, whether they are buried or cremated, where they are buried or their ashes are scattered/stored, wake arrangements and any other personal details or touches they want included.

A good End of Life Care Plan is focussed on living well and planning for the end of the person's life. End of life planning should ideally take place with the person themselves while they are still able to be involved with assistance from family, carers and people in their support network in partnership with the treating doctor(s). Where a person does not have this informal support, and a Public Guardian is already appointed to support a person's decision making, they may have a role in End of Life Care Planning.

An online resource has been developed by a number of universities with Government assistance called 'Talking End of Life with people with intellectual disability' (TEL). This suite or resources is available at: [Talking End of Life... with people with intellectual disability](#).

A person does not need to be unwell or have a terminal diagnosis to develop An End of Life Care Plan.

How to complete an End of Life Care Plan?

Refer to the [NDIS LWB 5573 End of Life Care Plan Quick Reference Guide](#) for step by step guidance on how to complete the [NDIS LWB 5571 End of Life Care Plan](#) template.

Where to save an End of Life Care Plan?

A completed End of Life Care Plan must be saved in the person's CIRTS record under Plans and Assessments > Plans > End of Life Care Plan.

Diagnosis of a terminal or chronic health condition that has an end stage

When a person's health condition has deteriorated or they have been reviewed by a doctor and have been given a terminal diagnosis, the treating doctor is responsible for informing the person, their person responsible, the family, and the GP (if not the treating doctor) of the person's diagnosis. After diagnosing a terminal condition, or a chronic health condition that will result in death, the treating doctor will present the person we support and family with treatment options.

The person has the right to seek a second opinion or information from other sources about the condition and treatment options. The person we support, and if needed, their person responsible, decide on the management approach in collaboration with health care providers.

Where to record a person's diagnosis?

The person's diagnosis should be recorded in their CIRTS Record under Health > Diagnosis > Medical > Ongoing.

Select the relevant diagnosis or select Other and describe using free text.

Treatment and Support Plans

Once the person has been diagnosed with a terminal illness, they may be prescribed active treatment in an attempt to lengthen their life. Those involved in the person's care and support should discuss the agreed treatment and care plan with the person or, where appropriate, their substitute decision-maker, to ensure there is a shared understanding of what management and support is required.

In a Shared and Supported Living (SSL) environment, the Line Manager should ensure that those who support the person know about the diagnosis and are aware of how to implement the treatment plan with respect to how it affects the person's lifestyle and supports required.

All prescribed treatments and support plans become part of the person's Health and Wellbeing Plan including their End of Life Care Plan. Staff must ensure they provide support to the person as directed within the support plans.

When staff become aware of changes in the person's support needs, they should support them to be reviewed by their GP or treating doctor for re-assessment of the support plans. The treating doctor will need to determine the review period for the Palliative Care plan in line with the person's declining health.

Treatment decisions

The decision to withdraw active treatment can only be made by the treating doctor in consultation with the person or their substitute decision-maker (e.g. person responsible or appointed guardian). In cases where the person we support does not have decision-making capacity, treatment should only be withdrawn where the treating doctor has confirmed that further treatment would be futile or unreasonably burdensome for the person.

Given the serious and irreversible consequences for the person, it is important that:

- Treating doctor(s) clearly explain to family members the available options, including active treatment;
- Treatment limitation decisions are informed by the people who know the person well, including where relevant, disability support staff. LWB staff should provide background information to the treating doctor but must not have any role in decisions about treatment;
- Maximum efforts are made to address any issues that are influencing the treatment decision, including options for providing support to reduce distress and pain;
- Any stakeholder with concerns about the treatment limitation decisions – including health practitioners and disability services staff – can consider whether an application needs to be made for the appointment of an alternative substitute decision-maker¹.

Where to save treatment plans and decisions in CIRTS?

Treatment plans and decisions must be saved in the person's CIRTS record under Plans and Assessments > Palliative Care Plan/DNR.

Palliative Care

Palliative Care is specialised care provided for people living with and dying from a terminal condition and for whom the primary goal is quality of life. It reduces suffering through early identification, assessment and treatment of pain, physical, emotional, social, cultural and spiritual needs and optimises comfort and dignity through support provided to the person, their family and carers.

Palliative Care also includes access to grief and bereavement support for families, carers and staff during the life of the person and following their death.

Specialist Palliative Care Services

Specialist Palliative Care Services are services provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with people who have a

¹ NSW Ombudsman – Deaths of people with disability in residential care August 2018
NDIS LWB 5570 End of Life and Palliative Care -
Procedure.docx
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terminal condition. Specialist Palliative Care Services are provided in care settings including Shared and Supported Living (SSL), community, home, hospitals, aged care homes, hospices and palliative care units.

Specialist Palliative Care Services work by providing:

- direct care to a person with complex needs;
- consultation based services to a person being cared for by primary care providers; and
- support and education to services providing end of life care.

The [National Palliative Care Service Directory](#) provides information about specialist Palliative Care Service Providers, State or Territory Palliative Care Organisations and Community Support Agencies.

How to develop a Palliative Care Plan?

Refer to the [NDIS LWB 5575 Palliative Care Plan Quick Reference Guide](#) for guidance on completing a Palliative Care Plan template in consultation with their treating doctor(s).

The treating doctor, GP or Specialist Palliative Care Service is responsible for directing Palliative Care which addresses the control of pain, management of other symptoms and support for psychological, social and emotional issues including spirituality.

Note: The treating doctor and other health professionals involved in directing the support to be provided are responsible for completing the specific medical diagnosis and palliative care support sections of the plan.

A range of people may be involved in providing Palliative Care Services including the GP, surgeon, medical or radiation oncologist, palliative care specialist, pastoral care worker, nurse, social worker, allied health professional, pharmacist, support workers, family members and volunteers.

LWB staff members who know the person well complete the non-medical support sections of the plan in consultation with the person we support, their family and any other important people.

Resuscitation Plans

LWB's approach to recording whether a person wishes to be resuscitated or not is for that information to be recorded within the [NDIS LWB 5574 Palliative Care Plan](#) regardless of whether the person is considered to be 'Palliative'.

Where a person has capacity to determine their own resuscitation, treatment and support requirements, they may also develop an Advance Care Directive – refer to the Advance Care Directive section on page 8 for further information.

Where a person does not have capacity to determine their own resuscitation options, their Authorised Decision Maker may make decisions on their behalf as part of the Palliative Care Planning process.

Note: LWB seeks to apply ethical principles and best practice standards for substitute decision making. Accordingly, no LWB staff member will act as an authorised decision-maker for any person that they support. LWB staff will support decision making by focusing on resources and support that enables a flexible approach to enhance each person's choice and control by strengthening opportunities for them to be part of a collaborative network of relationships that influence how and what decisions will be made.

Resuscitation includes a spectrum of interventions that may be given in an emergency to revive someone who would otherwise be likely to die within a very short space of time. Resuscitation is not limited to cardiopulmonary resuscitation (CPR); it may also include measures such as supplemental oxygen, intravenous fluids and non-invasive ventilation.

When a Palliative Care Plan is developed for a person, resuscitation does not need to be addressed, however, the template allows for decisions to be documented if they have been made. Where the person / their Authorised Decision Maker does wish to record a decision about resuscitation, it must be discussed with the treating doctor(s) overseeing the person as part of the Palliative Care Planning process. Recording decisions about resuscitation reduces the need to make decisions at the time of a medical emergency and helps ensure the person's wishes are respected.

A Resuscitation Plan should be as specific about the exact interventions that should or should not be given to the person we support. It should document all relevant time-critical clinical decisions, such as what life-sustaining interventions should be performed, and under what conditions. Where interventions will be withheld, these interventions must be listed specifically in the Plan.

The Resuscitation Plan may also specify specific approaches to resuscitation will not take effect until a certain point in time. For example, in the case of a progressive terminal illness, the Plan may state that resuscitation measures should only be withheld once the treating doctor determines death is imminent. In this case, the treating doctor can document the date where afterwards, staff must not give resuscitation.

Resuscitation Plans are considered when a person moves away from medical treatment or intervention towards a palliative approach to care. Resuscitation Plans are referred to in each state as follows:

- ACT – Goals of Care and Resuscitation Plan
- NSW – Resuscitation Plan
- NT – *within Advance Personal Plan only (person has to have capacity to develop plan)
- QLD – Acute Resuscitation Plan
- SA – Resuscitation Plan

- TAS – Medical Goals of Care Plan (resuscitation is addressed within)
- VIC – Goals of Care Plan – limitation of medical treatment)
- WA – Not For Resuscitation (NFR)

A completed Resuscitation Plan:

- Refers to the person's pre-planning such as their End of Life Care Plan and Palliative Care Plan
- Is made in consultation with the person we support and their family, Person Responsible and/or substitute decision-maker.
- Takes into account the person's clinical status, as well as their wishes and goals
- Can only be developed by the treating medical officer in consultation with the person and their family, Person Responsible, or Authorised Decision Maker.

Once developed, a Resuscitation Plan is a definitive statement of whether and in what circumstances the specified resuscitation measures should be given or withheld. It should be followed by everyone involved in the care and support of the person.

Who can develop a Resuscitation Plan?

Where the person does not have decision-making capacity, the Resuscitation Plan should be developed in consultation between the person's Authorised Decision Maker (e.g. person responsible, appointed guardian) and the treating doctor(s). Legislation in each State and Territory determines who can act as substitute decision-maker in these circumstances – refer to the tables on pages 12 – 14 for further information.

Where the person does have decision making capacity, decisions about resuscitation can be recorded within an Advance Care Directive – refer to the Advance Care Directive section on page 8 for further information.

While the law recognises that substitute decision-makers can give valid consent to medical treatment, including resuscitation measures, on behalf of the person concerned, it is less clear whether they can authorise the withholding of life-sustaining measures such as resuscitation interventions. In such cases, the Resuscitation Plan should not require resuscitation measures to be withheld unless the treating medical practitioners have confirmed, based on the person's clinical circumstances, that further medical treatment would be futile or unreasonably burdensome for the person.

Palliative Care Plans in Shared and Supported Living (SSL) environments

A Palliative Care Plan that has been developed in consultation with the person we support and their treating doctor(s) should be read in conjunction with the person's End of Life Care Plan if one has been developed.

Every person living in a LWB SSL service who has a diagnosed terminal illness or a progressive advanced disease must have the [NDIS LWB 5574 Palliative Care Plan](#) developed and reviewed with their treating doctor(s).

How to support a person with a Palliative Care Plan?

The Palliative Care Plan should provide information about the level and type of support that can be provided by LWB support workers including nursing staff.

It is important that Line Managers ensure support workers and nursing staff are aware of the plan, read the plan and understand their roles and responsibility in providing care as determined within the plan by the treating doctor(s).

Support Workers and nursing staff should attend any required training, follow the instructions in the Palliative Care Plan and notify their Line Manager if they have any difficulty in understanding their responsibilities.

The Line Manager must ensure they bring any changes to the Palliative Care Plans to the attention of their teams to ensure support workers and nursing staff continue to understand their responsibility in relation to communication with the treating doctor or team, life saving measures to take, first aid requirements and notifying ambulance and health services when the person's condition declines.

Advance Care Directive

Advance Care Directives are also known as Advance Health Directives in South Australia, Advance Personal Plan in Northern Territory and a Health Directive in the Australian Capital Territory.

An Advance Care Directive is a document, recognised by legislation in some states and territories that sets out legally binding directions given by a person (the person we support) about the treatment that should or should not be given, in anticipation of a time when the person is unable to express those preferences because of illness or injury.

Important Information for people with disability

Generally, people with capacity who have determined how they wish to be supported as their capacity diminishes regarding health, palliative care lifesaving interventions including resuscitation can document these within an Advance Care Directive.

However, Advance Care Directives can only be made by a person about themselves. The person making the Advance Care Directive must have full capacity to do so. People who lack capacity to make informed decisions are not able to make an Advance Care Directive. A person born with a significant intellectual disability would not be able to develop an Advanced Care Directive.

No one, including an Authorised Decision Maker, Person Responsible, Appointed Guardian or Power of Attorney can make an Advance Care Directive for another person.

Unfortunately, Doctors often use the terminology 'Advance Care Directive' when directing a person's family to document instructions about resuscitation for their family member. Where the person does not have capacity to make and record these decisions, an Advance Care Directive cannot be made – instead, the Authorised Decision Makers decision about resuscitation must be recorded within the [NDIS LWB 5574 Palliative Care Plan](#) template (Resuscitation Section) and supported and signed by the Health Professional.

Who can develop an Advance Care Directive?

An Advance Care Directive can only be made by a person who has capacity and who is 'competent' to make their own health care decisions when the Advance Care Directive is drafted. That is, they must have full capacity, be able to understand, retain and weigh up the relevant information and then make a choice(s), in preparation for a time when they may not have the capacity to make such decisions.

An Advance Care Directive including a Resuscitation Plan will be legally binding in those states and territories which recognise in legislation the legal effect of Advance Care Directives and will provide strong evidence of the individual's preferences in states and territories with no relevant legislation.

Where a person has made an Advanced Care Directive, they should be encouraged to review it annually to determine if it still matches their wishes.

How to support a person with an Advance Care Directive?

An Advance Care Directive developed by a person during the time they had capacity must be followed explicitly. The Line Manager should ensure all staff are aware the Advance Care Directive exists, what it covers and what they need to do in relation to informing appointed decision-makers, medical and Ambulance Services.

CIRTS instructions – Palliative Care, Resuscitation, Advance Care Directive

A completed Palliative Care Plan, Resuscitation Plan or Advance Care Directive addressing Palliative Care requirements must be saved in the person's CIRTS record under Plans and Assessments > Plans > Palliative Care Plan/DNR.

A printed copy should also be located where staff members, ambulance officers and attending medical professionals can quickly and easily refer to it.

First Aid

Where a person without a Resuscitation Plan is found to be unconscious, an ambulance must be called, and staff must perform First Aid including appropriate resuscitation until the ambulance arrives.

Where a person with a Resuscitation Plan or Advance Care Directive is found to be unconscious and the ambulance is called, staff must inform the ambulance service of the Plan and must follow the directions within the Plan in relation to resuscitation and other First Aid while they wait for the ambulance to arrive.

Where certain resuscitation measures are contra-indicated for a person by their treating health professional (e.g. CPR for someone with severe osteoporosis), this should be documented in the person's Resuscitation Plan and also in the person's CIRTTS record under Plans and Assessments > Palliative Care Plan/DNR.

Note: Where a person has a terminal diagnosis and a Palliative Care Plan with instructions relating to resuscitation, First Aid should still be given in the event of a non-illness related emergency such as choking or drowning until ambulance paramedics arrive.

Death of a Client

Please refer to the National LWB [Responding to a Client Death Policy Guideline](#) for step by step instructions on how to respond to the death of a person we support.

Authorised Decision Maker / Person Responsible or Appointed Guardian

The details of a person's substitute decision maker e.g. Person Responsible, or appointed guardian must be saved in their CIRTTS record under Network > New Network Member > New Network Connection > Key Decision Maker.

Where a person does not have an Authorised Decision Maker

Where a person we support does not have capacity to provide consent for themselves and does not have an appropriate person to act as an Authorised Decision Maker, that is, Person Responsible, they will need to apply to their state's tribunal to have a guardian appointed to support them with health and medical treatment decisions.

Refer to Pages 12 - 14 for descriptions of appropriate people to act as Authorised Decision Makers for a person without capacity.

Tribunal	Contact Details
<p>NSW Civil and Administrative Tribunal (NCAT) Guardianship Division PO Box K1026, Haymarket NSW 1240 DX11539 Sydney Downtown</p>	<p>1300 006 228 – press 2 for Guardianship Division matters Main Switch: 02 9556 7600 Interpreter Service (TIS) 13 14 50 National Relay Service: 1300 555 727 email: gd@ncat.nsw.gov.au</p>
<p>Victorian Civil and Administrative Tribunal GPO Box 5408 Melbourne VIC 3000 Ausdoc DX210576 Melbourne</p>	<p>1300 01 8228 Interpreter Service (TIS) 13 14 50 email: humanrights@vcat.vic.gov.au</p>
<p>Australian Capital Territory Civil and Administrative Tribunal GPO box 370 Canberra ACT 2601</p>	<p>02 6207 1740 email: tribunal@act.gov.au</p>
<p>South Australia Civil and Administrative Tribunal GPO Box 2361 Adelaide SA 5001</p>	<p>1800 723 767 email: sacat@sa.gov.au Urgent after hours: 08 8342 8200</p>
<p>Queensland Civil and Administrative Tribunal GPO Box 1639 Brisbane Qld 4001</p>	<p>1300 753 228 8:30 – 3pm email: enquiries@qcat.qld.gov.au</p>
<p>Guardianship and Administration Board - Tasmania The Registrar Guardianship and Administration Board GPO Box 1307 Hobart TAS 7001</p>	<p>1300 799 625 (local) 03 6165 7500 (interstate) email: guardianship.board@justice.tas.gov.au</p>

Tribunal	Contact Details
<p>Western Australia State Administrative Tribunal GPO Box U1991 Perth, WA 6845</p>	<p>1300 306 017 08 9219 3111 email: sat@justice.wa.gov.au</p>
<p>Northern Territory Civil and Administrative Tribunal Casuarina: PO Box 41860 Casuarina NT 0810 Alice Springs: PO Box 1745 Alice Springs NT 0870</p>	<p>1800 604 622 08 8944 8720 email: agd.ntcat@nt.gov.au</p>

Hierarchy of appropriate people able to give consent for health and medical decisions where a person has no capacity to provide consent.

Start at the top of list beginning with 1. to identify the most appropriate person in the hierarchy. If no appropriate person exists, refer to the Advance Care Directive section on page 8 for further information.

State	Hierarchy
<p>New South Wales - NCAT NSW Civil and Administrative Tribunal</p>	<ol style="list-style-type: none"> 1. Enduring Guardian (appointed when person had capacity) 2. Guardian appointed by NCAT 3. Default decision-maker - Person Responsible <ol style="list-style-type: none"> 3.1 Spouse – close relationship 3.2 An unpaid carer 3.3 A close relative or friend <p>Note: A Power of Attorney can only make financial decisions and cannot make decisions about health care or medical treatment.</p>
<p>Australian Capital Territory - ACAT ACT Civil and Administrative Tribunal</p>	<ol style="list-style-type: none"> 1. Attorney appointed under Enduring Power of Attorney for health care matter 2. Directions made in a Health Direction 3. A guardian or guardians appointed by ACAT 4. Default decision-maker - Health Attorney <ol style="list-style-type: none"> 4.1 Person's Domestic Partner – close relationship 4.2 Unpaid carer

State	Hierarchy
	4.3 Close relative or friend
Victoria - VCAT VIC Civil and Administrative Tribunal	<ol style="list-style-type: none"> 1. Medical treatment decision maker appointed by the adult 2. A Guardian appointed by VCAT to make medical treatment decisions 3. A default decision maker <ol style="list-style-type: none"> 3.1 Person's spouse or domestic partner 3.2 Primary carer in a care relationship and who has principal responsibility for the person's care (does not include paid carers, volunteers etc.) 3.3 The oldest child of the person 3.4 The oldest parent of the person 3.5 The oldest adult sibling of the person
Tasmania - GAB Guardianship and Administration Board	<ol style="list-style-type: none"> 1. Enduring Guardian (appointed when the person had capacity) 2. A Guardian appointed by the Board 3. Default decision-maker - Person Responsible <ol style="list-style-type: none"> 3.1 ≤ 18: Spouse or parent 3.2 Guardian incl: Enduring 3.3 Spouse – close relationship 3.4 Unpaid carer 3.5 Close friend or relative <p>Note: If Person Responsible refuses to give consent – Health Professional can apply to Guardianship and Administration Board for its consent to treatment.</p>
South Australia - SACAT SA Civil and Administrative Tribunal	<ol style="list-style-type: none"> 1. Medical Attorney (appointed when the person had capacity) 2. Enduring Guardian 3. Guardian appointed by SACAT 4. Default decision-maker - Person Responsible <ol style="list-style-type: none"> 4.1 Guardian with power to consent to medical treatment 4.2 Close relative including through kinship rules 4.3 Domestic Partner 4.4 Adult friend – close friend 4.5 Adult who oversees the person's ongoing day to day supervision care and wellbeing 4.6 SACAT – via application
Western Australia - SAT	<ol style="list-style-type: none"> 1. Enduring Guardian (appointed when the person had capacity) 2. Guardian appointed by WA SAT

State	Hierarchy
<p>WA State Administrative Tribunal</p>	<p>3. Default decision-maker - Person Responsible 3.1 Spouse or de facto partner 3.2 Nearest close relative 3.3 Unpaid primary provider of care and support 3.4 Any other person over 18 with a close relationship with the person</p> <p>Note: if there is no one available or suitable in this list and a treatment decision is needed, the health professional can apply to the SAT for the appointment of a guardian.</p>
<p>Northern Territory - NTCAT NT Civil and Administrative Tribunal</p>	<p>1. Guardian appointed by NTCAT 1.1 Anyone over 18 who the tribunal believes is suitable to act as guardian 1.2 The Public Guardian 1.3 The Public Trustee</p> <p>Note: NT does not recognise “default decision-makers” where no one has been formally appointed.</p> <p>In some cases, the NTCAT will also have power to act as decision-maker in relation to consent decisions including the power to consent to or refuse consent to treatment.</p>
<p>Queensland - QCAT QLD Civil and Administrative Tribunal</p>	<p>1. A guardian or guardians appointed by QCAT 2. An attorney appointed under Enduring Power of Attorney (appointed when person had capacity) 3. Default decision-maker - Statutory Health Attorney 3.1 Spouse or partner – close relationship 3.2 Unpaid carer over 18yrs 3.3 Close relative over 18yrs</p> <p>Note: where there is no appropriate decision maker, the Public Guardian will act as the default decision-maker.</p>