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Family &
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Services

End of Life Care Planning Guidelines

Summary: The End of Life Care Planning Guidelines is a good practice guide for supporting the present or future care needs of a person with disability and a life-limiting condition.





End of Life Care Planning Guidelines

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1 End of life care planning

The End of Life Care Planning Guidelines embody the principles of legal and human rights found in the New South Wales Disability Service Standards (the Standards), the commitment to deliver culturally responsive services to Aboriginal people under the Aboriginal Policy Statement (the Statement), and the person centred guiding principles of the ADHC Health and Wellbeing Policy.

The Guidelines are provided to support people with disability to exercise their rights and entitlements under the Standards and Statement. The Guidelines describe how ADHC supports the person and family to direct end of life care planning, and to experience quality end of life care under the guidance of their 'usual' General Practitioner (GP)¹ and other health specialists.

Good planning supports the person with disability to understand dying and death as part of the natural cycle of life.

It is important and good practice to have discussions about, and record, the person's values, wishes and expectations for the future. This knowledge ensures that the family, friends, and those providing care are aware of the person's wishes.

The recording of end of life care decisions can occur in many different ways for example; formally (medically authorised and legal documents/instructions) or informally (such as gathering ideas in the planning process) or recording changes on a Lifestyle Plan or documenting a person's wishes in a Living Well Plan.

More formal documents with specific instructions about end of life care, such as an, Advance Care Directive, Advance Care Plan, Palliative Care Plan, Resuscitation Plan, and Treatment Plan, are completed on specific templates (see Tools and Templates) or have certain requirements (see Other Resources).

The planning process can be facilitated using Person Centred tools (see Tools and Templates) and the outcome of the planning can be presented in any format the person understands. Plans that contain more general information about the person's end of life care, for example; the Living Well plan or information adapted to their Lifestyle Plan, can be documented in any format the person understands and that reflects their communication style.

People usually have no control over when they die, however planning allows a person the freedom to exercise control over the circumstances of their death. A number of key activities should occur during planning:

- Providing appropriate information about present and future support options and choices

¹ [Medicare](#) defines the person's 'usual' GP as: 'The GP (or a GP in the same practice) who has provided the majority of services to the patient in the past 12 months, and/or is likely to provide the majority of services in the following 12 months'.

- Consulting with the person, family, person responsible and health professionals
- Appointing a substitute decision maker, if required
- Recording and communicating the person's preferences, values and wishes for end of life care

Planning for end of life care can be facilitated using person centred planning approaches. Refer to Section 7 for an explanation of different plans and documents.

1.1 Communication

Initiating end of life discussions can be difficult. However, there are different life stages and events or triggers that can prompt a conversation around end of life planning, for example, diagnosis of a chronic disease with an end stage or life limiting health condition, a significant life event or milestone such as marriage, retirement, reaching a certain age or making a will.

Before discussing end of life care planning, ensure the person has a current Communication Profile which clearly describes the person's communication methods and styles.

Use the person's Lifestyle Planning meeting or My Health and Wellbeing Plan review as opportunities to initiate end of life discussions. The person's Lifestyle Plan could evolve into an End of Life Care Plan.

1.2 Person centred approach

Use the person's preferred way of communicating to maximise participation in end of life care planning, and keep the person at the centre of the conversation, and decisions, that are made about end of life care.

Every person can be involved in making choices about their life in some way. Make time to sit with the person and the family, and using the person's communication system, explore what is important to them now and in the future. Plan to have the conversation in a place where the person is comfortable and able to relax.

Some useful questions might be:

- What are the person's hopes and wishes for the future?
- What are the hopes and wishes of the family (see definition in section 7) for the person's future? (all members to contribute their views according to their preferred level of involvement)
- What would a good end of life look like?
- Who are the important people in the person's life?

It may be helpful to put together a “Personal Life Story” with the person.

Person Centred Thinking tools can be used for end of life planning to initiate discussion (See Other Resources) and help the person respond to changes in their life as they arise.

Useful tools are:

- Decision Making Profile and Agreement
- Hopes and Dreams
- Hopes and Fears
- Important To and Important For
- Good day / bad day
- History map
- Living Well workbook
- Action plan.

The person’s preferences for end of life care could include some of the following:

- What the person would like to do or achieve in the final stages of life.
- Recording their life history and important memories, including the family’s story.
- Spiritual and cultural needs and rituals, traditions and taboos.
- Where the person would like to spend their final days and with whom.
- Treatment goals and feeding alternatives the person would prefer as their health diminishes.
- The decisions that need to be made and how the person would like to be involved in the process.
- Identifying an individual responsible to make medical and treatment decisions for the person.
- Plan for dispersing the person’s belongings and precious items after death.
- Choosing an individual to help arrange their finances and other affairs.
- The person’s preferred arrangements at death – ceremonies, rituals, music, readings, style of funeral, place of burial or instructions for ashes.
- How the person would like to be remembered.

1.3 Shared planning when people lack capacity to make decisions

A person's decision-making capacity can diminish as a result of illness, and it is important to be aware and provide additional support for the person to make decisions at this time, if it is needed. Refer to the Decision Making and Consent Policy and related resources in the Lifestyle Manual.

Shared planning assists with supported decision making and is a partnership between the person, family, and others who know the person well, including staff and other carers.

Their combined knowledge can assist health care professionals to plan care that is consistent with the person's wishes and values.

1.4 Cultural and Linguistic Diversity

People bring their values, beliefs and experiences with them when they relocate to another country. The person and family's behaviour, attitude, preferences and decisions about end of life care planning, are influenced by culture and religious practices.

A person's cultural and religious preferences for end of life care planning should be ascertained when planning starts. Demonstrate respect and sensitivity by considering:

- their perspective on death and dying
- their perspective on health and suffering
- their perspective on palliative care
- their acceptance of Western health care practices and their use of alternative traditional practices
- the role of spiritual and religious beliefs and practices in the person's life and end of life preferences and decisions
- the role of the family, including who is considered as part of the family
- how the person and their family communicate and whether an interpreter is required
- any words or expressions that are taboo when discussing illness and dying
- the person's role in problem solving and decision making.

Build trust, and practice good communication when exploring the beliefs, values and practices of the person and family. Demonstrate respect, appreciation and sensitivity about the topic of death. Be prepared to discuss and record what is learned over several meetings.

1.5 Aboriginal and Torres Strait Islander People

Late diagnosis of disease in Aboriginal people is common, with many entering the chronic or end stage of disease before it is diagnosed. Cultural sensitivity is fundamental to a person centred approach when proposing end of life care planning with Aboriginal people. It is important to understand their core values of family and kinship, sharing, the cyclic concept of life and death, and relationship to the land.

To support Aboriginal and Torres Strait Islander people with end of life care planning in ways that are supportive and empowering, the following should be considered:

- Enquire who the appropriate contact person is for discussing issues around death and the provision of consent if required.
- Determine how the issue of death and dying is viewed in the person's community, and record how to communicate appropriately about sensitive or taboo issues.
- Confirm whether the person or family would prefer to work through an Aboriginal Liaison Officer and what services they will need to perform e.g. notifying the family of the person's death. It may be inappropriate for a non-Aboriginal person, known or unknown to the family, to discuss any issues about the person and death with the family member directly.
- Record whether the family wishes to perform any ceremonies related to death and dying. Note who will be involved and what supports and environment are required.
- Understand that family and friends have roles and responsibilities around death practices and ceremonies.
- The family must be informed in advance that a Coronial enquiry is required by law for anyone from a disability service who dies. This will not stop the family's rituals but it may delay some parts of them.
- Discuss whether financial assistance is required for a ceremony or burial – refer to Death procedures for further information. For information and financial assistance regarding funeral services contact the NSW Aboriginal Lands Council website.
- In preparation for death, a gathering of the family may occur as part of the ceremony to help the spirit leave the person and move away. The extended family gatherings may be large for this ceremony, ensure there is enough space and privacy for this to occur.
- The time of death is very significant for Aboriginal people. Cultural protocol for notifying the designated family member is extremely important at this time. The nominated service representative or an Aboriginal Liaison Officer must contact the designated family member.

See Other Resources for links to Aboriginal specific support services.

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

2.1 Informing the person and person responsible about the diagnosis

It is the responsibility of the treating doctor to inform the person, the person responsible, the family, the GP and other support people, of the person's diagnosis. When a carer or support person is not present at the appointment with the treating doctor, information about the diagnosis is sought from the person responsible. The person responsible informs those involved in the person's support, of the agreed treatment and care options, and any other relevant information.

After diagnosing a terminal condition, or a chronic health condition that will result in death, the treating doctor will present the person and family with some treatment options. The person's health condition and prognosis will determine the options for treatment and care. The person, and if needed the person responsible, decide on the management approach, in collaboration with other health care providers.

When the person and family are making decisions about treatment it is a good time to consider the person's end of life care plan to see if their earlier decisions still apply.

In an accommodation support services environment, once the person has been diagnosed with a terminal illness, the line manager should ensure that those who support the person know about the diagnosis. They will need to consider how to implement the treatment plan, the other service providers involved in the management of the person's care, and how it affects the person's lifestyle. The line manager may wish to engage other service providers who are part of the person's support team to provide education and training for particular aspects of care.

2.2 A second opinion

A person has the right to seek a second opinion or information from other sources about the condition and treatment options. In some cases, the person, the person responsible or family, may want a second opinion, or the treating doctor may suggest seeking a second opinion for further advice, or confirmation of the diagnosis.

Seeking a second opinion is a good decision if the person or family are concerned that they are not being given accurate or complete information to assist in their decision about treatment.

2.3 Linking the person's changing needs to their Lifestyle Plan

Goals previously identified in the person's Lifestyle Plan will need to be reviewed as the person's health needs change. The person may wish to continue using their Lifestyle Plan as a way of identifying support wishes and needs, or change to a Living Well Plan, a combination of both, or something of their own choosing.

3 Treatment and support plans

3.1 Recording treatment plan and other support plans

The person, family, and person responsible must have access to the person's treatment plan and any other relevant documentation. All prescribed treatments and support plans become part of the person's current health plans.

Treatment and support plans should be inserted into Section C of the person's My Health and Wellbeing Plan (see Volume 1 of the [Health and Wellbeing Manual](#)). Observations about the person's health are recorded in the Health Learning Log in Section B of the My Health and Wellbeing Plan.

Review of the treatment advice

Treatment or support plans prescribed by the treating doctor should be reviewed in line with policy review requirements. The ADHC Health Planning Procedures review cycle is quarterly or more often if the person's support needs change. Changes that trigger a review can be an improvement or deterioration in the person's condition.

Changes in the person's support needs should trigger a review by the GP or treating doctor for a re-assessment of the support plans.

3.2 Referral to Specialist Palliative Care Services

If the person's support needs have reached a stage where the GP cannot provide the level of support the person requires, a referral to Specialist Palliative Care Service is appropriate.

Consent must be obtained from the person or the person responsible to approach Specialist Palliative Care Services (see Other Resources). If consent is provided, the GP or treating doctor makes a referral. If consent is not provided by the person and their health care needs are affecting their quality of life, and they are not thinking clearly, consent may need to be given on their behalf by their person responsible.

4 Palliative care

4.1 Developing a palliative care plan

Palliative care is specialised care provided for all people living with and dying from a terminal condition and for whom the primary goal is quality of life. It optimises comfort and dignity and provides support to the person, the family and carers.

The treating doctor, GP or specialist palliative care service is responsible for developing a palliative care plan for the person. Development of the plan includes the person, family, person responsible and other support people.

In an accommodation support environment, the support worker and line manager include all the essential people in the planning process who are important to the person. Documents and information that support the planning process could include:

- the person's One Page Profile, Communication Profile, Communication Chart, Decision Making Profile and Agreement and other tools used in Lifestyle Planning (refer to the Lifestyle Manual)
- the person's current My Health and Wellbeing Plan and all the person's health and wellbeing information
- the level and type of support that can be provided by the accommodation support service.

There is no specific template prescribed by ADHC for a palliative care plan and the treating doctor or palliative care service will document the person's support needs using their own recording methods. An Authorised Adult Palliative Care Plan, NSW Ambulance services and Authorised Paediatric Care Plan (can be used for children and young people) templates is available (see Tools and Templates) and can be used.

It is important that carers (including both paid and unpaid) and support workers understand the plan, and their roles in the coordination of services and care. Support workers must provide palliative care under the guidance of a health professional.

The palliative care plan is reviewed according to the prescribing health professional's instructions, otherwise it is reviewed each quarter, or sooner if the person's health changes.

Written documents relating to a person's palliative care are incorporated in the My Health and Wellbeing 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 and volunteers.

In the absence of a palliative care plan, the person must have a treatment plan that describes the support the person requires.

The GP has access to Medicare Item 721, the GP Management Plan to develop a treatment plan. Further information on the GP Management Plan can be found in the Chronic Disease Guidelines (in Health and Wellbeing Policy and Practice Manual Volume 2).

5 Capacity and participation

All people have the right to make plans about their end of life care, be informed of their condition, prognosis and treatment options. People also have the right to refuse information about their prognosis.

Capacity is unique to each person and situation, and should not be determined simply on the basis of a type of disability or a one-off assessment. A person has capacity to consent if she or he is able to understand the general nature and effect of a particular decision or action, and can communicate an intention to consent (or refuse consent) to that decision or action.

5.1 Making decisions when the person lacks capacity

A person's capacity can fluctuate over time and is specific to each decision. Where there is doubt about a person's capacity to make a particular decision, supported decision making must first be fully explored. In situations where a person has been unable to make a decision even with support, a legally appointed guardian with the specific decision making function may be required to make particular decisions. Refer to ADHC Decision Making and Consent Policy and Guidelines 2014 and the Capacity Toolkit for further guidance (see Other Resources).

5.2 The importance of early planning

Early planning for end of life care is an opportunity for the person or in the case where a person needs support, utilising **supported shared planning** to identify the things they would like, or not like, to happen at the end of life. These decisions are recorded for the information of the person responsible and any health professionals involved in making treatment decisions.

5.3 Who can (legally) make treatment decisions for a person's who does not have capacity?

When a person lacks decision making capacity and it is not an emergency, all health care practitioners are required by law to consult and seek consent to treat from the 'person responsible'. For people 16 years and older, the person responsible is determined according to hierarchy within the *Guardianship Act 1987* (NSW).

See: the NSW Civil and Administrative Tribunal (NCAT) [Fact sheet – Consent to medical or dental treatment](#)² and ADHC Decision Making and Consent Policy and Guidelines.

5.4 When a person does not have a person responsible?

If the treatment being proposed is not minor or urgent, then an application can be made to the Guardianship Division of the New South Wales Civil and Administrative Tribunal (NCAT) to appoint a guardian with medical and dental consent functions (see Decision Making and Consent Policy and Guidelines - Other Resources).

5.5 Advance care directives and plans, and the law

An Advance Care Directive (ACD) is medically authorised instructions developed by a person with decision making capacity to be used in circumstances where they lose capacity. The ACD is legally enforceable in NSW. It is a record of decisions or value statements that describes a person's future preferences relating to medical treatment. An ACD cannot be developed on behalf of another person such as, a 'person responsible'.

A person responsible can develop an **Advance Care Plan (ACP)** completed with the person (**supported shared planning**), or on behalf of a person. An ACP is the documented outcome of an advance care planning process. An ACP records known and perceived preferences of the person about health and personal care and treatment goals at end of life.

Anyone who knows the person well can record known preferences of the person. When a person is approaching end of life this information is provided to appropriate persons when making end of life care decision on their behalf. (See Other Resources, End of life decisions, and the law and clinical practice website).

5.6 Palliative care planning where the Public Guardian is the substitute decision maker

Where the Public Guardian (PG) is appointed as the substitute decision maker the PG is not able to consent to an Advanced Care Directive. The PG can facilitate a palliative care plan under the recommendation of the treating specialist, if medical intervention is not going to improve the person's quality of life.

Early planning is important as it captures the person's thoughts and wishes about end of life care, and it can inform a palliative care or resuscitation plan (see below).

² NSW Civil and Administrative Tribunal (NCAT) Fact Sheet – Consent to medical and dental treatment http://www.ncat.nsw.gov.au/Documents/gd_factsheet_consent_to_medical_or_dental_treatment.pdf

When the PG is involved in palliative care planning, a record of current health issues and prognosis, and the proposed palliative care treatment is provided to the guardian. A support worker or line manager will facilitate provision of the information from the treating specialist and others involved in the care of the person.

The support worker or line manager will make referral to a Specialist Palliative Care service (see Other Resources) to provide the medical specialist and others involved in the care of the person with the [Public Guardian – Palliative Care Plans: What we need to know from you \(checklist\)](#)³.

The PG will require a contact list of all the treating medical staff, allied health professionals and the accommodation support service's Team Leader and Coordinator. The PG will contact all parties to discuss the person's quality of life, the impact and effect of current and proposed treatments as needed.

5.7 Resuscitation Plans

Resuscitation Plans are considered when a person moves away from aggressive medical intervention towards a palliative approach to care.

A Resuscitation Plan is a medically and legally enforceable authorised order. It nominates when to use or withhold resuscitation measures, and documents other time critical clinical decisions related to end of life. Resuscitation Plans must be followed by all care staff.

The Resuscitation Plan was formerly known as a No CPR Order.

A Resuscitation Plan:

- refers to the person's pre-planning (such as End of Life Care Plans or Advance Care Plans or Directives)
- is made in consultation with the person and family
- takes into account the person's current clinical status, as well as the wishes and goals of the person
- can only be developed by the treating medical officer in consultation with the person and their family.

Other health care professionals (including nurses) cannot be delegated the task of informing people or obtaining consent for resuscitation planning.

NSW Health Resuscitation Plans are valid for use by NSW Ambulance staff in all situations involving patient contact. A hard copy of the Resuscitation Plan should

³ Public Guardian Palliative Care Plans: What we need to know from you
http://www.publicguardian.justice.nsw.gov.au/Documents/Palliative_Care_Checklist.pdf

be kept at the front of the person's health care record (see Other Resources 4 – Resuscitation Plans in End of Life Decisions – NSW Health).

6 Resolving end of life conflicts

End of life conflict is defined as disagreement which occurs about the goals of care or treatment decisions at the end of life. It commonly occurs where such conflict is not resolved by further discussion between the person, family and the treating clinicians, as appropriate.

End of life decision making is a process based on assessment, findings and deliberation. Its purpose is to reach agreement on treatment and support with the person, family or person responsible, and the treatment team.

Good planning practice is to start planning early and ensuring that the right people are involved from the beginning.

Disagreement within families of people without decision making capacity, or between families and the health care team, about whether resuscitation is appropriate, can create significant barriers to good planning.

Disagreements can occur because of:

- ineffective communication about the person's end of life preferences
- unclear expectations
- avoidance of end of life discussions
- time constraints
- risk management concerns
- uncoordinated care
- personal responses to death and dying
- misunderstanding about ethical and legal issues, and
- lack of knowledge and understanding of a person's cultural needs.

Prompt conflict management will maintain focus on the best interests and outcome for the person. Delays in resolving conflict may cause unnecessary discomfort, distress and pain to the person, and reduce their quality of life when they need it most. If a family requires support with conflict management, they should seek support from a mediation service (see Other Resources).

7 Explanation of terms

Advance Care Directive (ACD)

An ACD is a written advance care plan recognised by common law and authorised by legislation that is completed and signed by a **person with decision making capacity**. It was formerly known as a “living will”. The ACD should inform a Resuscitation Plan.

An ACD records the person’s preference for future care and appoints a substitute decision maker to make decisions about health care, and personal life issues management.

ACDs **have legal status** and are recognised under the law. The ACD comes into effect when the person loses the capacity to make decisions e.g. the person is in a coma.

In NSW an ACD usually contains details of a person’s health management preferences

- any values and beliefs that may guide future treatment
- instructions regarding the future use or restriction of particular medical treatments, and details of who the person wants to make decisions for them when they are no longer able.

Advance Care Plan (ACP)

An advance care planning discussion will often result in an ACP. The ACP records the person’s preferences about health and preferred outcomes. It may be developed on the person’s behalf, and is prepared from the person’s perspective to guide decisions about treatment and care. It may be verbal or written. It should inform a Resuscitation Plan or Palliative Care Plan.

Advance care planning

Advance care planning involves thinking, discussing and documenting. It generally involves ongoing conversations between the person, family and the treating health professionals over a period of time. These conversations enable planning for future deterioration in the person’s health when they become unable to make decisions about treatment and care.

Capacity

Capacity is unique to each person and situation, and should not be determined on the basis of a type of disability or a one-off assessment. A person has capacity to consent if she or he is able to understand the general nature and effect of a particular decision or action, and can communicate an intention to consent (or refuse consent) to the decision or action.

Capacity can be affected by a range of things including health, mood, time of day, setting and relationship with the person seeking consent. The person may not have had opportunities to make decisions, or express their preferences in a way

that others understand. These factors are considered in decision making and consent giving processes.

Opportunities to increase a person's decision making skills, confidence and capacity should be maximised. This may include improving communication systems, supporting the person to understand the decision making process, and providing opportunities to practice making decisions.

Refer to the Decision Making and Consent Policy and related resources (in Health and Wellbeing Volume 3) for more details.

Chronic health condition

Chronic disease is an illness that is prolonged in duration, does not often resolve spontaneously and is rarely cured completely. Chronic diseases are complex and varied, often having more than one cause, and can create a burden of disease on the community. While some chronic diseases are responsible for premature death, others result in some form of disability. Features common to most chronic diseases include:

- complex causes with multiple factors leading to their onset
- long development period during which there may be no symptoms
- prolonged course of illness, perhaps leading to other health complications
- Associated functional impairment or disability.

For more information, refer to the Chronic Disease Guidelines in the Health and Wellbeing Practice Manual, Volume 2.

End of life

End of Life is defined as the period including dying, death, and the post-death ritual.

End of life care

End of life care is person centred care provided to support a person at any time in the final period of their life, and addresses the person's physical, social, emotional and spiritual needs, support for the family, and care of the body after death.

End of life conflict

End of life conflict is defined as disagreement which occurs about the goals of care or treatment decisions at the end of life, where such conflict is not resolved by time, and further discussion between the patient, the family and the treating clinicians, as appropriate ([Conflict Resolution in End of Life Settings Report](#), NSW Health 2010⁴)

⁴ <http://www.health.nsw.gov.au/patients/acp/Pages/conflict-resolution.aspx>

End of Life Care Planning

End of Life Care Planning is planning for future care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when the person is unable to make or communicate decisions. This allows the person to choose the type of care and support to live and die well in their preferred place.

The planning process allows the person with disability to understand dying and death, as part of a natural cycle of life and direct self determined wishes.

Where a person has a limited capacity to make decisions, families can assist them to make plans through **supported shared planning**.

Enduring Guardian (EG)

An EG is someone appointed by a person to make personal (including medical) or lifestyle decisions on their behalf when they are not capable of doing so for themselves. EG's and those appointed by the Guardianship Division of the NCAT may make end of life decisions on the person's behalf. The appointment of an EG comes into effect when the appointing individual loses capacity to make personal or lifestyle decisions. People can choose which decisions (called functions) they want their EG to make. These functions are governed by the *NSW Guardianship Act 1987*. Refer to the ADHC Decision Making and Consent Policy.

Expected Death

An expected death is when a person has a progressive, advanced disease or terminal illness, or the person chooses not to pursue curative treatment. Refer also to definition of 'Unexpected death'.

Family

In the context of this Policy and the related resources, 'family' refers to any person who is a relative or friend having a close and continuing relation with a person, and who has a personal interest in the welfare of the person. It can include the 'person responsible', and partner, including same sex and de facto partners.

Goals of care

The general goal of medical treatment is the health and wellbeing of the person. The specific goal of medical treatment may, in the circumstances, be cure of an illness, relief of the symptoms of an illness, stabilisation of the person in a satisfactory condition or improvement in the way the person dies.

Guardianship Division of the NCAT

This was formerly known as the Guardianship Tribunal. As of 1 January 2014, the Guardianship Tribunal became a Division of the New South Wales Civil and Administrative Tribunal (NCAT). The Guardianship Division is a specialist disability division within NCAT. The Division conducts hearings to determine applications about adults with a decision making disability who are incapable of making their own decisions and who may require a legally appointed substitute decision maker for contact details see Other Resources.

Health Care Plan

A plan prescribed by a health professional such as the person's usual GP which outlines advice, recommendations and timeframes for the completion of health actions for the person. In ADHC operated accommodation support services, the Health Care Plan is known as the My Health and Wellbeing Plan.

Health care professionals

Doctors, specialists, nurses and allied health workers who are trained and recognised by an appropriate registering body.

Life-sustaining treatment

Life-sustaining treatment is any medical intervention, technology, procedure or medication that is administered to prevent the moment of death, whether or not the treatment is intended to affect life-limiting diseases or biological processes. These treatments may include, but are not limited to, mechanical ventilation, artificial hydration and nutrition, cardiopulmonary resuscitation or certain medications (including antibiotics).

Lifestyle Plan

A 'living' plan that belongs to the person and which represents their personal wishes and lifestyle choices. The Lifestyle Plan includes an Action Plan which describes all the actions that are needed to help the person achieve their goals and dreams. Refer to the Lifestyle Policy and Practice Manual for more details.

Living Well Plan

A Living Well Plan is a person centred resource that can be used to complement or replace the person's Lifestyle Plan, and is developed with the person for their end of life care.

Palliative approach

A palliative approach refers to medical care for improving the quality of life of a person with a terminal condition and includes the family if the person wants their involvement. It reduces suffering through early identification, assessment and treatment of pain, physical, emotional, social, cultural and spiritual needs.

Palliative Care

Palliative care is specialist care provided for all people living with and dying from a terminal condition and for whom the primary goal is quality of life. It optimises comfort and dignity and provides support to the person, the family and carers.

Palliative Care Plan

A Palliative Care Plan is a written plan developed with the person, the family or guardian, the person responsible and the services involved in providing care to the person. The Palliative Care Plan aims to support the person, their person responsible and family or guardian to direct and influence the person's treatment and quality of life.

Person centred approach

The Person centred approach ensures that the person with disability is central to any planning and decision making that determines her or his future care. According to her or his preference and ability, the person chooses the level of participation in planning, and is encouraged and supported as much as possible, to direct the planning process.

Person responsible⁵

The *NSW Guardianship Act 1987* establishes who can give valid consent for medical treatment for a person who lacks the capacity to and are aged 16 years or over. The Act establishes a hierarchy for determination of who is the Person Responsible as follows:

- The person's lawfully appointed guardian (including an Enduring Guardian) but only if the order or instrument appointing the guardian extends to medical treatment
- If there is no guardian, a spouse including a de facto spouse and same sex partner with whom the person has a close continuing relationship
- If there is no such person, a person who has care of the person (as a patient)
- If there is no such person, a close friend or relative.

Primary care provider

Primary care providers include all health and other services that have a primary or 'first contact' relationship with the person. In the context of End of Life Care Planning, it refers to GPs, community nurses, staff of residential care facilities and multipurpose centres, Large Residential Centres and Specialist Support Living (both ADHC funded and operated) and includes other specialist services and staff relevant to the person's medical condition.

Primary palliative care services

A primary palliative care service refers to the group of services which cover the continuum of care required for a person with a terminal condition such as General Practitioners, community nurses, allied health staff and other specialist services relevant to the person's condition. They may have existing relationships with the person, or be providing interventional care in conjunction with specialist palliative care services.

Rapid response

This refers to an immediate review undertaken by an individual or multidisciplinary team of healthcare professionals who have been trained and assessed to hold an

⁵ NCAT Person responsible factsheet: http://www.ncat.nsw.gov.au/Documents/gd_factsheet_person_responsible.pdf

advance level of competence in resuscitation and stabilization of patients. A Rapid Response call must be made if the patient's observations fall into the 'Red Zone' of the NSW Health Standard Observation Charts.

Resuscitation

Resuscitation encompasses a spectrum of emergency interventions such as supplemental oxygen, intravenous fluids and non-invasive ventilation. It is not limited to cardiopulmonary resuscitation.

Resuscitation Plan previously known as No CPR Orders

A Resuscitation Plan is a medically legally enforceable, medical authorised order to use or withhold resuscitation measures and documents other time critical clinical decisions related to end of life.

For more information and template see Other Resources – Resuscitation Plans in End of Life Decisions – NSW Health.

Shared planning decision-making model

Shared planning is a supported decision making model for use when a person lacks decision making capacity, and provides additional support for the person to make decisions. Supported decision making is a partnership between the person, the family and others who know the person well. Their knowledge can assist to plan care that is consistent with the person's wishes and values.

Senior treating clinician

The senior treating clinician is the one who assumes overall management responsibility for a patient's treatment plan and clinical care. This may be a Visiting Medical Officer in private or hospital practice, a staff specialist, a GP, or a senior Registrar in training.

Specialist Palliative Care services

Specialist palliative care services are provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with people who have a terminal condition. Specialist palliative care services are provided in care settings including community, home, hospitals, aged care homes and hospices and palliative care units.

Specialist palliative care services work in three key ways:

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

Substitute decision maker

Substitute decision maker is a collective term for those appointed or identified by law to make substitute decisions on behalf of a person whose decision-making capacity is impaired. A substitute decision maker may be appointed by the person

(e.g. one or more Enduring Guardians appointed by the person under statutory provisions), appointed for (on behalf of) the person (e.g. a guardian appointed by the Guardianship Division of the NCAT), or identified as the default decision maker by the *NSW Guardianship Act 1987* (such as a spouse or carer) as the Person Responsible.

Unexpected death

An unexpected death is when a person dies suddenly and unpredictably.

8 Legislation

The NSW legal context in which end of life decisions are made:

- *Disability Inclusion Act 2014*
- *The Guardianship Act 1987*
- *The Crimes Act 1900*
- *Mental Health Act 2007*
- *Children and Young Persons (Care and Protection) Act 1998*

9 Policy and Practice Unit contact details

You can get advice and support about this Policy from the Policy and Practice Unit, Contemporary Residential Options Directorate.

Policy and Practice, Service Improvement Contemporary Residential Options Directorate ADHC policyandpracticefeedback@facs.nsw.gov.au

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