End-of-life Care Decisions: Practice Guideline

The Role of the Office of the Public Guardian (OPG)
The OPG is a statutory body within the NSW Department of Justice and represents people with impaired decision making ability. People represented by the OPG are appointed by the Guardianship Division of the NSW Civil and Administrative Tribunal (NCAT) or Supreme Court. The OPG makes health and lifestyle decisions for people who are unable to make decisions with informal support. The OPG’s decision making authority is detailed in the represented person’s guardianship order. For more information refer to the fact sheet About the Public Guardian.

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1. Introduction

This document describes:
- end-of-life care and treatment
- the role of guardians when considering end-of-life care and treatment
- what processes guardians need to follow when making decisions for people under guardianship
- how guardians contribute to end-of-life care and planning when not making a formal end-of-life decision.

All people have the right to be involved in decisions about their own lives. People with a cognitive impairment may need decision making support to be fully involved in that process.

When a person is represented by the Public Guardian the guardian must make decisions that promote the person’s welfare and interests. Central to the Public Guardian’s decision making is knowing the person’s will and preference about the decision being considered.

All people have the right to die with dignity. People with disability have a right to access the same medical services and treatment that is available to the rest of the community, irrespective of age, place of residence, socio-economic status, cultural background or legal status.

The Guardianship Act 1987 NSW states people should not be deprived of treatment simply because they are unable to give consent, and that treatment should only be given to promote the person’s health and wellbeing. End-of-life treatment should ensure the person is comfortable and pain free, and should not expose the person to excessive burden.
2. Practice guideline

2.1. Decision making overview

When the Office of the Public Guardian is contacted by a medical practitioner about an end-of-life matter, guardianship staff ('guardians') must first establish the reason for contact. Is it:

- to seek consent to treatment, including
  - Active treatment
  - Treatment withdrawal or limitation
  - End of life care plan or resuscitation plan
- to consult with the Public Guardian
- to advise about a clinical decision already made
- to seek information about a represented person or guardianship authority
- about something else?

When the reason for the contact is established, the guardian should discuss it with their supervisor or Regional Manager. The delegation for end of life decisions is with the Regional Manager. Refer to the decision making delegation guideline.

When considering end-of-life decisions or planning:

- **Limiting or withdrawing treatment** does not necessarily require the consent of a guardian. Guardians may advocate for the person’s care needs to be met but they can’t direct clinical decisions.
- If the medical practitioner seeks consent to withdraw or limit treatment, this should be consented to in the form of a written end-of-life or resuscitation plan. A critical source of information for what should be included in a written plan is the Public Guardian’s Planning for end-of-life checklist.
- If the consent is for **active medical treatment** only, this can be consented to under a medical and dental consent function.
- If an end-of-life decision is not being sought, it is still appropriate for the guardian to participate in planning discussions with the person, the treating doctor or team and others, such as family members, carers and other professionals. This is in line with NSW Health’s end-of-life decision making model.
- Guardians should follow the Public Guardian’s Decision making guideline by gathering views and information and making the necessary decision or recording relevant information if a decision is not required.
2.2. Active treatment

Active treatments at the end of a person’s life are prescribed or given to ensure the person is pain free and comfortable rather than to prolong life. For example, medications may be given to manage symptoms of pain, respiratory distress or agitation.

Consent to active treatment can be given by a guardian with the appropriate delegation, under a medical and dental consent function. Consent can be given in the absence of an end-of-life care plan. The same consent process is followed as for any other medical consent, such as:

- treating practitioners assess whether the person can give consent themselves or if the person responsible needs to consent
- applications for major medical treatment must be made in writing
- Consent requests should include information about the person’s condition, treatment options, alternative treatments, and risks and benefits of treatment.

2.3. Withdrawing or limiting life-sustaining treatment

Treatment ‘withdrawal’ includes, for example, removing a Percutaneous Endoscopic Gastrostomy (PEG) or other feeding tube, ceasing dialysis or withdrawing a breathing tube. Treatment ‘limitation’ may include not transferring a person to an intensive care unit, not providing cardio-pulmonary resuscitation (CPR), or not inserting a feeding or breathing tube.

Limiting or withholding treatment does not necessarily require the consent of a guardian. NSW Health end-of-life policy and guidelines require medical practitioners to consult with guardians and family when considering or making end-of-life decisions for patients, referred to as a ‘collaborative approach’ to end-of-life care.

Guardians cannot direct practitioners to withdraw or offer treatment the practitioner believes is not clinically indicated. If the guardian disagrees with a decision to withdraw treatment, they may advocate for treatment to be reinstated or request a second opinion.

**Seeking a second opinion**

Maureen has uterine cancer that spread to her bones and other organs. Dr Foster assessed the risk to Maureen of actively treating (radio and/or chemotherapy) was much greater than not treating. Maureen was unable to understand basic information about her condition due to advanced dementia.

Dr Foster explained Maureen’s medical condition and treatment options with her guardian and family. However, Dr Foster did not seek consent as not providing treatment is a clinical decision. Some of Maureen’s family were not convinced treatment should be withheld. The guardian decided to request a second opinion from another oncologist.
2.4. Advance care plans and planning

An Advance Care Plan is a record of the treatment and care a person will receive at the end of their life, including active treatments, treatment limitation and treatment withdrawal. Advance care planning is a collaborative process between the person, their family, friends, and medical and health professionals, including with a guardian if one is appointed. Plans can be verbal but written plans are a more reliable record. The plan can be made by or with the person and should record the person's treatment choices and preferences to the fullest extent possible. An advance care plan is not a legal document.

For patients unable to make decisions about their end-of-life care, NSW Health has adopted a consensus-building approach. This approach includes the treating team talking to the person, carers, family, friends, and medical and health professionals to make a plan with and for the person. For more detail refer to the NSW Health End of Life Care Guideline.

The Public Guardian supports this model but notes a guardian with a health care function has a specific authority to give or withhold consent to any plan that is developed. The guardian may not exercise that authority, depending on the circumstances. A guardian is most likely to make a decision about an advance care plan when:
- a medical or health care professional requests consent
- there is conflict about the proposed end-of-life treatment and care.

The guardian should ensure the plan addresses the topics included in the Public Guardian's End-of-life checklist. If a guardian does not have a health care function, they may still have a 'planning ahead' role by helping identify the person's needs, values and wishes.

Just as a medical practitioner would consult with the patient, the Public Guardian expects to be involved in the end of life decision making process.

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**Guardian’s consent to an advance care plan**

Andrea is a 24 year old woman with a degenerative dementia-like illness.

The geriatrician's clinical view is Andrea should not be resuscitated if she has heart failure as it would result in a further and considerable decline in her quality of life.

The geriatrician developed an end-of-life care plan in consultation with the Public Guardian, Andrea’s family and other medical and non-medical supporters. The Public Guardian consented to the plan: it struck the right balance between Andrea’s quality of life and medical intervention. It enabled her to live a life that maximised her pleasures and allowed her the dignity of taking risks.

**Advance Care Plan with no guardian consent**

George lives in an aged care facility and has chronic health problems. Over time, George’s GP and specialist have discussed his treatment options with him. The specialist arranges a meeting with George, his family, doctors and other health professionals with a view to making an advance care plan. George talks about the type of care he would like to receive, including where he wants to be cared for and by whom.

The specialist develops a resuscitation plan for George, in line with George’s wishes. George, his family and carers are given a copy so everyone is clear about the care he wants. Over time George reviews his plan and makes adjustments to fit with changes to his health needs, wishes and available treatment and support options.
2.5. NSW Health resuscitation plans and planning

NSW Health resuscitation plans, previously known as ‘No CPR orders’, authorise medical officers working in NSW Health facilities to use or withhold resuscitation measures and document other aspects of treatment relevant at end-of-life. (NSW Health’s Policy Directive, Using Resuscitation Plans in End of Life Decisions, 2014)

NSW Health resuscitation plans are:

- medical orders
- developed when the person is nearing death in consultation with the person and their person responsible
- can only be created by NSW Public Health Organisations (including acute facilities, sub-acute facilities, ambulatory and community settings, and NSW Ambulance).
- are not valid for community patients under the medical care of a doctor that is not a NSW Health staff member. General Practitioners with admitting rights are considered NSW Health staff.

Guardians should follow the same decision making process for resuscitation plans as for advance care plans.

NSW Health’s resuscitation policy (Section 2.2) explains CPR should not be instituted when:

- there is a clearly stated, adequately informed and properly documented or verbally expressed refusal by a person with decision-making capacity.
- the person has no capacity to make this decision and the Attending Medical Officer has properly documented their decision to withhold resuscitation, in consultation with the person responsible.
- the Attending Medical Officer judges that resuscitation offers no benefit or where the benefits are small and overwhelmed by the burden to the person.

Making and implementing a resuscitation plan

Dr Singh is Wafaa’s cardiologist and is aware that Wafaa is at high risk of a heart attack due to chronic health conditions. Dr Singh decided to complete a resuscitation plan for Wafaa, and did so in collaboration with Wafaa, her family, carers and guardian. Wafaa says she does not want treatment when informed by Dr Singh that there was a high risk that resuscitation after a heart attack would result in her being in a worse condition.

Later, during a hospital admission, Wafaa has a cardiac arrest. As agreed with family and guardian, and line with Wafaa’s plan, CPR is not performed.
3. Advance care directives

Advance care directives are different to advance care plans.

Advanced Care Directive

An advanced care directive (ACD) is a legally binding instruction about future medical treatment, made by a person with decision-making capacity, for a time in the future when they may not have that capacity.

The ACD documents a person’s wishes, so that they can be followed when the person cannot make or communicate decisions. An ACD can be verbal but a written directive will more clearly document the person’s will and preferences, especially when there is a dispute or doubt about what the person wants. ACDs do not need to be witnessed or registered. It is important to inform those who may need to act on an ACD, such as the person’s treating doctors and person responsible that it exists.

A person with cognitive impairment may be supported to make an ACD but no one can write or direct an ACD on behalf of another person.

Legal advice should be sought if there are concerns about the validity of an advance care directive.


What is the link between an ACD and enduring guardianship?

Enduring guardianship can be used to appoint a substitute decision-maker of a person’s choosing. Some people prefer the option of an enduring guardian to act as their ‘voice’ and express their likely wishes when they lose capacity, rather than make a binding advanced care directive.

If a person has appointed an enduring guardian and made an ACD, the enduring guardian cannot make medical decisions or consent to any plan that is against what the person has said they want in their ACD. For more information about enduring guardianship please see the Public Guardian’s guidebook, Enduring Guardianship: Your Way to Plan Ahead.
4. Urgent treatment

A medical practitioner does not need consent for urgent treatment. Urgent treatment is defined in the Guardianship Act as treatment to save a person’s life, prevent serious damage to the person’s health or to prevent their suffering.

Urgent treatment cannot be given where consent has been declined and/or where a medical practitioner has access and assessed a valid advance care directive.

Treatment and care needs at end-of-life can usually be planned for. Planning and discussion avoids the need for urgent treatment decisions, which can be distressing.

5. Time-frame for decision making

The Public Guardian’s standard is to respond to requests for medical consent within 24 hours. Sometimes a decision may take longer than 24 hours because of the guardian’s responsibility to seek information and the views of the person (where possible) and other significant people. The Public Guardian can be contacted after-hours when consent is needed before the next business day, but in most cases the normal process of consultation needs to be followed.

The Public Guardian will often ask the treating team to seek the views of family members about treatment. The Office of the Public Guardian does not replace family members. It is important for family to have their questions about a person’s current condition and prognosis answered by a medical practitioner (unless there are reasons for not talking to a specific person). This approach is consistent with NSW Health guidelines.

6. Disagreements with an end-of-life decision

The Public Guardian seeks the views of people significantly affected by an end-of-life decision before making a decision, either directly or via the treating team.

Occasionally, people may disagree with the Public Guardian’s decision. The Public Guardian’s decisions are reviewable; information about the review process is available in this factsheet: Your right to review a decision.

The Guardianship Division of the NSW Civil and Administrative Tribunal can review guardianship orders, including enduring guardianship appointments. The Guardianship Division can consider requests for consent to treatment where there is no person responsible.

7. Death of person under guardianship: Public Guardian’s role

Guardianship authority ends when the represented person dies. The Public Guardian does not have any role in funeral arrangements or authority to make financial decisions.
In certain circumstances the Public Guardian may request an inquest into the
death of the person under guardianship.

Funeral arrangements should be discussed with the executor of the person’s will
or their family and friends or an appointed financial manager, for example NSW
Trustee and Guardian (which is not part of the Office of the Public Guardian). For
information about destitute funerals link to NSW Health statement: Destitute
Persons: cremation or burial Policy Directive.

8. References: law and policy

Guardianship Act 1987 (NSW) Part 5 and general principles (section 4)

Anti-Discrimination Act 1977 (NSW), particularly in relation to potential
discrimination based on a person’s age, physical and/or disability.

Euthanasia is illegal in New South Wales. Euthanasia is directly and intentionally
causing the death of a person in order to relieve that person’s suffering. See
section 31C of the Crimes Act 1900 NSW.

NSW Health Policy and Guidelines
- NSW Health GL2005_057 End-of-life care and decision-making: Guidelines
  (2005)
- NSW Health Policy Directive: PD2014_030 Using Resuscitation Plans in End-
of-life Decisions (2014)
- NSW Health Policy Directive: PD2008_012 Destitute Persons: cremation or
  burial (2008)
- NSW Health Making Advance Care Directives
- NSW Health Advance Care Planning website

Enduring Guardianship: Enduring Guardianship: Your Way to Plan Ahead

Enduring Power of Attorney in NSW relates to financial and property decisions
only. Enduring Powers of Attorney cannot make health and other guardianship
decisions on behalf of another person. For further information follow this link to
the NSW Land Registry Services.

Planning Ahead Tools
The NSW Government’s Planning Ahead Tools website contains information on
all aspects of planning ahead. It has comprehensive information on wills, powers
of attorney, enduring guardianship and advance care planning. Planning Ahead
Tools offers tailored information for individuals, health professionals and legal
professionals. The website includes interactive tools and links to useful
publications and resources: www.planningaheadtools.com.au