

Position statement

Protecting the human rights of adults with decision-making disabilities

Role of the Public Advocate as guardian of last resort with authority to make treatment decisions: Palliative care

The *Guardianship and Administration Act 1990* (the Act) recognises that people who are not capable of making reasoned decisions for themselves may need additional support and assistance not only to ensure their quality of life is maintained, but also to protect them from the risk of neglect, exploitation and abuse.

Under the Act, the State Administrative Tribunal (the Tribunal) may appoint a guardian for a person with a decision-making disability. Guardians are substitute decision-makers who make personal, lifestyle and treatment decisions in the best interests of people who are not capable of making reasoned decisions for themselves due to conditions such as dementia, intellectual disability, mental illness or an acquired brain injury.

The Tribunal can appoint the Public Advocate as guardian of last resort only when there is no one else suitable, willing and available to act as the person's guardian. The decision-making authority of the Public Advocate may be limited to specific areas such as treatment and accommodation (limited order) or it may apply to all personal, lifestyle and treatment related decisions (plenary order).

When appointed guardian of last resort with the authority to make **treatment decisions**, the Public Advocate is responsible for making decisions about any treatment proposed for the person.

In the Act at section 3 a '**treatment decision**' is defined as a decision to consent or refuse consent to the commencement or continuation of any treatment of the person.

In the Act, the term '**treatment**' refers to any medical, surgical or dental treatment or other health care, including life-sustaining measures and palliative care.

The Public Advocate, through the delegated guardian, will participate in discussions about treatment and has authority to consent or refuse consent to treatment following recommendations from the doctor and/or treating team. This includes making decisions about treatment options in relation to palliative care.

In the Act the term '**palliative care**' means a medical, surgical or nursing procedure directed at relieving a person's pain, discomfort or distress, but does not include a life sustaining measure.

To make any decision about treatment and healthcare, including palliative care, the Public Advocate must be appointed either as plenary guardian or appointed under section 45(2)(d) of the Act as limited guardian with authority to make treatment decisions for the represented person.

The Public Advocate Position Statement: *Role of the Public Advocate as guardian of last resort with authority to make treatment decisions* outlines the process followed by the delegated guardian in relation to making treatment decisions.

When making any treatment decision in relation to a represented person, the Public Advocate must always act in the best interests of the person as outlined in section 51 of the Act. This is done by advocating on behalf of the person, seeking to identify their previous views and trying to follow these where possible, liaising with family and friends and gathering their views about treatment.

This position statement looks at the specific considerations in relation to making decisions about palliative care, where this is the treatment option proposed by the treating health professional(s).

Palliative care

Palliative care is a form of treatment which ensures the total care of a person whose condition is not responsive to curative treatment. It includes the control of pain, proper hydration, adequate nutrition, medication to relieve distressing symptoms, the provision of nursing care and appropriate psychological, social and spiritual support.

Palliative care is often associated with end of life treatment. However, it has a broader use and may be recommended at other stages of a person's condition to relieve symptoms and to ensure the person is comfortable. When palliative treatment is used in this way it may play an important role in improving the person's quality of life over the course of their illness.

Palliative care may also be the recommended form of treatment for a person who is in the terminal phase of a diagnosed condition. At this stage, active treatment may be successful in relieving symptoms temporarily but the effects of their condition cannot be reversed by further active treatment.

Where palliative care is proposed as one of a range of treatment options, the Public Advocate will consider it as one of the recommendations from the treating professional. A person's treatment may include a combination of appropriate active treatment in addition to appropriate palliative measures.

For example, a person who has a terminal condition may be receiving palliative care for that condition but could have antibiotics to relieve a treatable infection. The main consideration would be that the treatment consented to, is that which is in the best interests of the represented person at the time treatment is required.

It is important to understand that a decision to consent to palliative treatment, which may include the withdrawal or withholding of certain treatment, is not about hastening the death of the person. The treatment decision will be made in accordance with good medical practice based on the needs of the person.

Although palliative care is not only about end of life care, in many cases it is the care consented to during the final stages of a person's life. In recognition of the serious nature of decisions involving end of life care and treatment, all decisions regarding palliative care will be authorised by the Public Advocate based on information obtained by the delegated guardian.

Advance Health Directive

Where a represented person has made an advance health directive, the Public Advocate cannot override any decisions made in the advance health directive, except in exceptional circumstances.

If the person has made a decision about palliative treatment in their advance health directive, the delegated guardian will inform the treating health professional of the decision and ensure the treating health professional has a copy of the advance health directive to show consent has been given for the treatment.

Where the person has an advance health directive which does not include a treatment decision in relation to the person's current circumstances, the Public Advocate is able to make the decision in the best interests of the person. However, the Public Advocate will refer to the advance health directive for evidence of the person's views or wishes about treatment which may have some relevance to the decision about palliative treatment.

The advance health directive should not be followed if there are concerns about its validity. The treating health professional is responsible for gaining informed consent, assessing if the advance health directive should apply and determining whether to follow the treatment decisions in an advance health directive. If the treating professional is not satisfied that the advance health directive applies, they should seek informed consent from another party.

If there is any doubt about the validity of the document, or a specific treatment decision, an application can be made to the State Administrative Tribunal for a decision on validity under section 110W of the *Guardianship and Administration Act 1990*.

When could palliative care be considered for a represented person?

At any time following a diagnosis it may be relevant to refer a person to be assessed for palliative care/treatment. There are a range of benefits to an early referral, which may be beneficial to the person as their condition progresses. These include:

- A palliative care specialist can discuss the situation and advise the person of their options. The patient can then consider these options and make some decisions about how they would like to receive treatment at various stages.
- The patient and their family can build a relationship with the palliative care specialist before the terminal phase of their illness.
- An ongoing involvement allows for regular assessment and a gradual increase in palliative measures alongside active treatment.
- A decrease in hospital admissions for symptoms which can be managed palliatively at home.
- Access to counselling and support through the palliative care system.

The Office of the Public Advocate will work with palliative care specialists throughout the course of a person's illness to ensure the person has appropriate palliative treatment alongside active treatment.

How is a decision made to consent to palliative care?

When the Public Advocate is asked to consent to a person receiving palliative care, the guardian will usually request a palliative care assessment be carried out and a palliative care plan be provided. This assessment can be done by the primary medical team caring for the person. A palliative care specialist/team can be accessed if the primary medical team is unable to provide the assessment, or if the Public Advocate considers that a second opinion would be beneficial.

A palliative care plan will usually include information about:

- the represented person's medical condition and prognosis
- the treatment options available (both active and palliative treatment)
- the recommendation of the treating professional for palliative care
- why the treating professional believes it is the appropriate form of care
- the proposed palliative care regime to be implemented in relation to the represented person
- a review date for the plan.

The delegated guardian will usually ask for the palliative care treatment plan verbally.

The palliative care plan will only be consented to if the Public Advocate is satisfied that the proposed treatment is in the best interests of the represented person.

The guardian will seek information from the treating health professionals about the timeframe within which a decision is required. Staff from the Office of the Public Advocate will endeavour to meet this timeframe, but must always ensure that all relevant information has been gathered before making a decision about any form of treatment, including palliative care.

The Public Advocate understands that during the decision-making process there will be times where the treating team commence some palliative treatments such as pain relief, to prevent the person from suffering pain or distress.

Voluntary Assisted Dying

A guardian cannot make a decision for a represented person under the *Voluntary Assisted Dying Act 2019*. Nothing in the *Guardianship and Administration Act 1990* authorises the making of a treatment decision, whether in an advance health directive or otherwise, in relation to voluntary assisted dying decisions.

Resuscitation decisions as part of a palliative care plan

When considering palliative care, the Public Advocate may also be asked to make a decision in advance in relation to cardio-pulmonary resuscitation including consenting to a 'not for resuscitation' order. The Public Advocate does not routinely sign 'not for resuscitation' forms, but will consider medical information about resuscitation, on an individual basis, as part of a palliative approach.

For people for whom cardio-respiratory arrest is an anticipated consequence of their illness, the Public Advocate may consent to a request to withhold cardio-pulmonary resuscitation, as part of a palliative care plan, when this is in the person's best interests and in line with medical advice and with the goals of care.

Under these circumstances, cardio-pulmonary resuscitation would be seen as futile treatment, which would not resolve the person's condition and may give rise to further complications if it was attempted.

For people for whom cardio-respiratory arrest is not anticipated, the Public Advocate expects that in the event of cardio-respiratory arrest, the treating practitioner will apply clinical judgement about the treatment to be provided. The Public Advocate understands that 'clinical judgement' would include consideration of details of the person's condition, physical frailty, the likely prognosis should resuscitation be attempted and any other relevant information that indicates that cardio-pulmonary resuscitation would prolong suffering and/or is medically futile.

Where a person has experienced cardio-respiratory arrest and treatment has been successful in reviving the person, the guardian will talk with the treating health professional to seek advice on how to manage future events. Where possible, members of the treating team, staff from a care facility or the delegated guardian from the Office of the Public Advocate will consult with the person's family and friends to gain their views about treatment and may seek a review of the palliative care plan based on changes to the person's condition.

Summary of palliative care decision-making by the Public Advocate

- The proposed care is consistent with the represented person's wishes and values, as expressed or gathered from previous actions including the treatment decisions within their advance health directive (if the person made an advance health directive).
- As far as possible, the delegated guardian from the Office of the Public Advocate seeks the views of the person concerned (or takes his/her previously stated views into consideration) and takes into account the views of family members and others who are important in the person's life.
- Any conflicting medical opinions about the represented person's diagnosis or proposed treatment are resolved by a specialist's assessment and where necessary, a second opinion is sought.
- The information required to make a decision is gathered by the delegated guardian, however the Public Advocate must provide, or refuse, consent to the decision about the palliative care plan, as the legally appointed substitute decision-maker.

The Public Advocate publishes position statements on:

- Decisions about treatment
- Restrictive Practices
- The role of the Public Advocate as guardian of last resort with authority to make accommodation decisions
- The role of the Public Advocate as guardian of last resort with authority to make treatment decisions
- The role of the Public Advocate as guardian of last resort with authority to make contact decisions
- **The role of the Public Advocate as guardian of last resort with authority to make treatment decisions: palliative care**
- Decisions about medical research
- The role of the Public Advocate as guardian of last resort with authority to make decisions about restrictive practices
- Role of the Public Advocate as guardian of last resort with authority to make decisions about services: NDIS

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The Office of the Public Advocate can be contacted after hours on 9278 7300 for urgent decisions.

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