

**PLEASE NOTE:** The following statement should be considered in conjunction with the NSW Health *Guidelines for end-of-life care and decision-making* and *Decisions relating to no cardio-pulmonary resuscitation orders*. In accordance with these guidelines, the Public Guardian expects to be consulted regarding all end-of-life, palliative care and 'no cardio-pulmonary resuscitation' decision-making.

### RELEVANT LEGISLATION

**NSW Guardianship Act 1987**, section 4 – General Principles require that:

- the welfare and interests of the person under guardianship should be given paramount consideration;
- the views of the person should be taken into consideration;
- the importance of preserving the family relationships and the cultural and linguistic environments of the person should be recognised;
- the person under guardianship should be protected from neglect, abuse and exploitation.

Part 5 of the Guardianship Act 1987 requires that consent for medical treatment be given only where the proposed treatment "promotes and maintains the health and well-being of the person". Under the Act a guardian is required to consider whether to give or withhold treatment when the treating medical practitioner has determined that a person cannot give their own consent and only after all relevant information has been obtained and considered. This includes the view of the person under guardianship. The views of their family, carers and others important in the person's life may also be sought.

The Act requires that people are not deprived of necessary medical or dental treatment merely because they lack the capacity to consent to the carrying out of such treatment.

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

This position statement does not refer to euthanasia that is, directly and intentionally causing the death of a person in order to relieve that person's suffering. Euthanasia is illegal in New South Wales.

### POSITION STATEMENT

A person with a disability has a right to the range of medical services and treatment available to the rest of the community irrespective of his or her age, level and nature of pre-existing disability, where they live, socio-economic status, cultural background or legal status. Many people under the guardianship of the Public Guardian are highly vulnerable because they are not able to adequately represent their own interests. The Public Guardian, with the appropriate function(s), has the authority to provide or withhold consent on a person's behalf and will advocate for the person's interests and for their access to necessary treatment and services.

The Public Guardian believes that a person with a disability has a right to die with dignity and in the company of friends and loved ones and where possible in circumstances consistent with the person's expressed wishes. When the treating medical practitioner has advised the Public Guardian that continued treatment is medically futile and as such, not in the best interests of the person, the Public Guardian may provide or withhold consent to treatment at end-of- life so that a person with a disability will not be in a position where he or she is subjected to treatment which may be burdensome, traumatic and intrusive, without therapeutic benefit and where the person is without the means to bring the treatment to an end.

### DISCUSSION

When appointed as guardian, that is, substitute decision maker, for a person under guardianship, the Public Guardian is in effect standing in the shoes of the person under guardianship in order to make the sorts of decisions that the person would otherwise make for themselves. Therefore, for the purposes of gaining legal consent to treatment and for health care decisions, the Public Guardian should be consulted, as the patient would be. This does not prevent the treating medical practitioner's clinical

decision making nor replace the need for consultation with the person under guardianship (if possible) or the person's family and friends.

When appointed with a medical and dental consent function, the Public Guardian may provide or withhold consent to requests for medical treatment on behalf of the person. Part 5 of the Guardianship Act 1987 provides the conditions under which consent must be sought.

When appointed with a health care function the Public Guardian may make decisions about the provision of health care on behalf of the person, for example consenting to a health care plan, seeking a second opinion or consenting to the withdrawal of treatment.

In situations regarding end-of-life care decisions, the Public Guardian generally expects requests for consent to be presented within the context of a palliative care plan. This position statement discusses the Public Guardian's expectations and responsibilities regarding palliative care, advance care planning and issues relating to treatment limitation, including 'no cardio-pulmonary resuscitation orders' and treatment withdrawal.

### **PALLIATIVE CARE**

Palliative care is the active total care of a person whose condition is not responsive to curative treatment. It involves coordinated services including the control of pain, hydration and nutrition, medication to relieve distressing symptoms, nursing care and the provision of psychological, social and spiritual support. Palliative care may include active treatment, treatment withdrawal and/ or limitation or a combination of these elements.

The Public Guardian may be asked to consent to treatments such as pain relief or sedation that may have the potential side-effect of hastening death. These treatments may only be consented to if the Public Guardian is satisfied that the proposed treatment promotes the person's health and wellbeing. Such proposals should be presented within the context of a comprehensive palliative care plan.

It is the Public Guardian's position that the proposed palliative care should be consistent with best practice palliative care and appropriately trained staff should be available to supervise this care. The proposed palliative care plan should ensure:

- a person's right to appropriate medical and allied treatment and intervention necessary for his/her medical condition is not diminished by the person having a pre-existing disability;
- medical treatment and intervention proposed for the person should be consistent with current best practice medicine for the person's medical condition;
- a second, or further specialist opinion may be sought, particularly if there are conflicting opinions about the person's condition or proposed treatment;
- efforts are made, where possible, to determine the current view of the person about a proposed treatment or procedure using a method of communication familiar to them;
- the previously expressed view of the person, either through an advance care directive or other documents if available, or through the views expressed by the person to family or close friends are sought and taken into consideration;
- the person's cultural and religious values and those of his/her family are taken into account;
- the views of partners and family members, and others important in the person's life are considered; and
- information is provided where appropriate to confirm whether or not a woman is pregnant.

### **The Public Guardian may consent to palliative care providing that:**

- the treating medical practitioner has determined that the person cannot give their own consent;
- the Public Guardian is authorised to consent to the person's medical treatment or health care under a current guardianship order of the Guardianship Tribunal or the Supreme Court;
- the treating medical practitioner has determined that continuing treatment is futile;
- the Public Guardian has sought the views of the person concerned (or has taken into consideration his/her previously stated views), as well as the views of family members, and others who are important in the person's life;

- the Public Guardian has been provided with information about the person's condition, possible alternative treatment strategies, the reasons why these treatments are considered not appropriate, the person's prognosis and any other relevant information required by the Public Guardian;
- palliative care is being proposed as the most appropriate treatment for the person given their medical condition and this has been confirmed by an independent specialist if required by the Public Guardian;
- details of the palliative care treatment plan have been provided by the treating team including:
  - where the palliative care is to occur;
  - the nature and extent of pain relief to be provided;
  - what medications, nutrition, hydration are to be provided; and
  - what counselling and psychological support is proposed for the person.

Requests for decisions will be responded to as promptly as possible. In some circumstances a decision may take more than 24 hours, given the Public Guardian's responsibility to consult with significant people before any decision is made or where a second opinion has been requested. The Office of the Public Guardian can be contacted after hours for matters that cannot wait until the next business day.

### Advance care planning

When appointed with a health care function the Public Guardian may consent to an advance care plan on behalf of a person under her guardianship. In making a decision about an Advance Care Plan the Public Guardian will consider the request in the same manner as a Palliative Care Plan.

It should be noted that the Guardianship Act does not give authority for the Public Guardian or any other substitute decision maker to make an *Advance Care Directive*<sup>1</sup> on behalf of another person.

### Treatment limitation

Where a medical practitioner considers that treatment/s are not clinically indicated for the person's medical condition, the decision not to provide treatment is a medical decision for the practitioner based on evidence about the person's current medical condition.

The Public Guardian expects that a senior medical practitioner would make such decisions where available and that evidence would include:

- the person's condition,
- the treatment available,
- the proposed treatment(s),
- the person's prognosis in terms of recovering from the condition, and
- any other information that indicates that treatment would likely prolong suffering and/or is medically futile.

Just as a medical practitioner would engage in discussions with the person, the Public Guardian expects to be involved in such discussions. This is in keeping with NSW Health guidelines.

### No cardio-pulmonary resuscitation orders

For people for whom cardiorespiratory arrest is an anticipated consequence of their illness the Public Guardian expects that the treating practitioner will consult with the Public Guardian and with the person's family and friends about the goals of care and preferences for treatment. Consultation is required by the NSW Health *Guidelines for end-of-life care and decision making (2005)* and *Decision relating to no cardio-pulmonary resuscitation orders (2008)*. The Public Guardian may require a request for no cardio-pulmonary resuscitation to be contained within a comprehensive palliative care plan.

For people for whom cardiorespiratory arrest is not anticipated, the Public Guardian expects that in the event of an arrest the treating practitioner will apply clinical judgement and consult with the Public

<sup>1</sup> An advanced care directive, sometimes called a "living will", is a written instruction by the patient documenting their wishes for future medical treatment. It only becomes effective if the patient loses the capacity to make his or her own treatment decisions. Family members, guardians or doctors cannot prepare advance care directives on the patient's behalf although they may be involved in advance care planning.

Guardian and the person's family and friends only where time permits. The Public Guardian understands that 'clinical judgement' would include consideration of details of the person's condition, the likely prognosis should resuscitation be attempted and any other relevant information that indicates that cardio-pulmonary resuscitation would likely prolong suffering and/or is medically futile. Such decisions would not be made on the basis of a person's disability.

### **Treatment withdrawal**

Under Part 5 of the Guardianship Act treatment should only be given where it promotes and maintains the health and well-being of the person. The decision to withdraw treatment is a clinical judgment. The proposal to withdraw treatment is made when a treating practitioner has determined that continued treatment is medically futile. If continued treatment is medically futile it is then considered that such treatment is no longer in the person's best interests. Such decisions should be made according to NSW Health Guidelines. The Public Guardian should be included in the process of consultation that occurs as part of the decision making process. If the Public Guardian disagrees with the decision to withdraw treatment she may advocate for reinstatement of the treatment and may request a second opinion.

### **CONSENT REQUESTS IN RELATION TO A PERSON WHO WAS UNDER GUARDIANSHIP AND WHO HAS DIED**

The Public Guardian is occasionally asked to make decisions in relation to a person who has died. For example, requests for consent to the following:

- an autopsy
- organ donation
- access to the body where a dispute exists
- funeral arrangements.

Because a guardianship order ceases to have any legal effect after the death of the person under guardianship, the Public Guardian does not have the authority to consent to any of these requests.

### **Inquests**

In certain circumstances the Public Guardian may request an inquest into the death of the person under guardianship.

### **Funeral arrangements**

If the Office of the Public Guardian is contacted in relation to funeral arrangements, the person making the inquiry will be advised, to contact the Office of the Protective Commissioner, or the private financial manager, if the person's financial affairs have been under a management order, or where there is no financial manager, the executor of the person's will, or the person's next of kin.

### **BACKGROUND MATERIAL**

*Guidelines for end-of-life care and decision-making* NSW Health 2005 [www.health.nsw.gov.au](http://www.health.nsw.gov.au)

*Decisions Relating to No Cardio-Pulmonary Resuscitation Orders* NSW Health 2008

[www.health.nsw.gov.au](http://www.health.nsw.gov.au)

*Using Advance Care Directives* NSW Department of Health 2004 [www.health.nsw.gov.au](http://www.health.nsw.gov.au)

*Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State* National Health and Medical Research Council, Australian Government 2008 [www.nhmrc.gov.au](http://www.nhmrc.gov.au)

*Post-Coma Unresponsiveness and Minimally Responsive State – A Guide for Families and Carers of People with Profound Brain Damage* National Health and Medical Research Council, Australian Government 2008 [www.nhmrc.gov.au](http://www.nhmrc.gov.au)

### **OTHER RELATED OPG POSITION STATEMENTS**

Determining whether to consent to proposed medical or dental treatment.

Valuing the cultural, linguistic and religious background of the person under guardianship.