7. Patients (16 years or over) who do not have capacity to consent

7.1. When does the Guardianship Act apply?

The *Guardianship Act 1987* applies to people aged 16 and over who are incapable of giving consent. The Act aims to ensure that people with a disability (such as an intellectual disability) are not deprived of necessary medical or dental treatment because they lack the capacity to consent to the carrying out of such treatment, and to ensure that any medical or dental treatment that is carried out on such people is carried out for the purpose of promoting and maintaining their health and wellbeing.

Consent for Minors aged 16 and 17 without capacity due to a disability can be obtained either under the *Guardianship Act 1987* or under the principles for consent for Minors in Section 8 of the Consent Manual.

7.2. The Person Responsible

The *Guardianship Act* 1987 establishes who can give valid substitute consent when a person is unable to consent to medical or dental treatment.

Section 33(2) of the *Guardianship Act* states that a person is incapable of giving consent if the person is incapable of understanding the general nature and effect of the proposed treatment or is incapable of indicating whether or not they consent to the treatment.

When a patient lacks decision-making capacity and the treatment is not required in an emergency, Health Practitioners must obtain consent from the Person Responsible.

The Person Responsible for a patient will be:

- 1. An appointed guardian (including Enduring Guardian) with the function of consenting to medical and dental treatment. If there is no-one in this category;
- 2. A spouse or de facto spouse (including same-sex partners) who has a close and continuing relationship with the person. If there is no-one in this category;
- 3. The carer or person who provides or arranges domestic services and care regularly or did so before the person went into residential care, and who is unpaid (note: the carers pension does not count as payment). If there is no-one in this category;
- 4. A close friend or relative, provided they are not receiving remuneration for any services provided.

Health Practitioners have an obligation to consult with the person highest on the hierarchy. If that person is not present, attempts should be made to contact them. If a Person Responsible does not wish to make medical treatment decisions for a patient, or does not have capacity themselves, this must be documented in the patient's Health Record. If this happens, the next person on the hierarchy can be approached.

If there is no Person Responsible available, or the Medical Practitioner has concerns that the Person Responsible is not acting in the best interests of the patient and the treatment proposed is not <u>minor</u> or urgent, then an application can be made to the Guardianship Division of NCAT for the Tribunal's consent to the treatment, or for the Tribunal to appoint a guardian who can consent to the treatment.

7.3. What is a guardian or Enduring Guardian?

A person, 18 years of age or above, may appoint a guardian or Enduring Guardian using the prescribed form available from the Guardianship Division of the NCAT, or a form with the same features and effect.

An appointment only has effect during a period in which the person needs a guardian (when the person does not have capacity).

The decisions that an Enduring Guardian may make on behalf of the person are specified in the document appointing the person. The person appointing the Enduring Guardian may limit the decisions that they can make. Health Practitioners should ask to review the appointment document to ensure that the Enduring Guardian has the power to make decisions in relation to medical or dental treatment. Where there is a guardian appointed (enduring or appointed by NCAT) and that guardian has authority to consent to medical and dental treatments, only the guardian can perform that function and the rest of the hierarchy of Persons Responsible cannot. If the guardian is not available or willing to act, NCAT needs to be contacted. However, where the guardian does not hold the authority to consent to medical or dental treatments then the next person on the hierarchy should be contacted.

Further guidance

• NSW Civil and Administrative Tribunal, Guardianship Division, *Information for Applicants Appointment of a Financial manager and/or guardian*

7.4. What happens if a guardian or Enduring Guardian was appointed outside NSW?

If a person has been appointed as guardian of another person in another State or Territory or in New Zealand, that guardian can apply to NCAT to have their status as guardian recognised in NSW.

If a person has been appointed as an Enduring Guardian in another State or Territory, they can automatically make decisions in NSW without needing to apply for recognition. If an Enduring Guardian has been appointed overseas, the NCAT will need to recognise their status.

Further guidance

- NSW Civil and Administrative Tribunal, Guardianship Division, Guardianship Division Fact sheets ncat.nsw.gov.au/publications-and-resources/fact-sheets/guardianship-division-fact-sheets.html#Enduring3
- Guardianship Regulation 2016, regulation 8

7.5. Requesting consent from the Person Responsible

A request to a Person Responsible for consent must specify the following information:

- the grounds on which it is alleged the patient does not have capacity to consent to medical treatment
- the particular condition of the patient that requires treatment
- the alternative courses of treatment that are available in relation to that condition
- the general nature and effect of each of the courses of treatment
- the nature and degree of the significant risks (if any) associated with each of these courses of treatment
- the reasons for which it is proposed that any particular course of treatment should be carried out.

These requirements will be met if the Consent – Substitute Consent for Medical Procedure/Treatment form is used and all fields are completed.

A request to a Person Responsible is to be made in writing. However:

- If the request is for major medical treatment, it may be made orally if it is not practicable to make the request in writing because of the need to provide the treatment quickly.
- If the request is for minor medical or dental treatment, the request may be made orally, if it is not practicable to make the consent in writing or the Person Responsible does not require the request for consent to be made in writing.

Where an oral request for consent is made for major treatment, it should be confirmed in writing using a Consent – Substitute Consent for Medical Procedure/Treatment form.

Health Practitioners must ensure that the Person Responsible has all the information they need to make an informed decision on behalf of the patient. In all cases, the Person Responsible must consider the views (if any) of the patient (including any objections the person may have to the treatment), the information provided by the person requesting consent and the objectives of the *Guardianship Act*.

A Health Practitioner who carries out treatment relying on the consent of a guardian or Person Responsible must keep a written record of the name of the person who gave consent, the date, any conditions on the consent and the treatment.

Further guidance

- NSW Civil and Administrative Tribunal, Guardianship Division, Consent to Medical or Dental Treatment Application Form
- NSW Health Guideline The Guardianship Application Process for Adult Inpatients of NSW Health Facilities (GL2017_013)
- NSW Public Guardian Medical and Dental Treatment

7.6. When is a consent application to the Guardianship Division of the Civil and Administrative Tribunal required?

An application to NCAT is required if one or more of the following apply:

- the treatment is Special Medical Treatment and it is not an emergency
- the treatment is major medical treatment or dental treatment and there is no Person Responsible or the Person Responsible is unable or unwilling to provide consent and it is not an emergency
- the patient is objecting to the proposed treatment (major or minor) and there is no appointed guardian authorised to override objections. In respect of minor treatment, NCAT approval is only required if the patient has no or minimal understanding of the treatment and the treatment will cause no distress or only some tolerable transitory distress (see section 7.9)
- the appointed guardian or Person Responsible is not acting in the patient's best interests. In this scenario, an application could also be made to the Supreme Court. It is recommended that advice from the Ministry of Health Legal Branch be sought prior to making an application to the Supreme Court.

Further guidance

- NSW Civil and Administrative Tribunal, Guardianship Division
- NSW Health Guideline The Guardianship Application Process for Adult Inpatients of NSW Health Facilities (GL2017_013)

7.7. Types of treatment under the Guardianship Act and consent requirements

The *Guardianship Act* makes different arrangements for obtaining consent depending on the level of intervention proposed. Distinctions are drawn between Minor treatment, Major treatment and Special Treatment.

Major treatment

In the Guardianship Regulation, major treatment is:

- 1. any treatment that involves the administration of a long-acting injectable hormonal substance for the purpose of contraception or menstrual regulation
- 2. any treatment that involves administration of a drug of addiction
- 3. any treatment that involves the administration of a general anaesthetic or other sedation, but not treatment involving:
 - sedation used to facilitate the management of fractured or dislocated limbs, or
 - sedation used to facilitate the insertion of an endoscope into a patient's body for diagnostic purposes unless the endoscope is inserted through a breach or incision in the skin or a mucous membrane.
- 4. any treatment used for the purpose of eliminating menstruation
- 5. any treatment that involves the administration of a restricted substance for the purpose of affecting the central nervous system, but not a treatment:
 - involving a substance that is intended to be used for analgesic, antipyretic, anti-Parkinsonian, anticonvulsant, antiemetic, anti-nauseant or antihistaminic purposes, or
 - that is to be given only once, or
 - that is a *pro re nata* (PRN) treatment (that is, given when required, according to the patient's needs that may be given not more than 3 times a month), or
 - given for sedation in minor medical procedures.
- 6. any treatment that involves a substantial risk to the patient (that is risk that amounts to more than a mere possibility) of (a) death; or (b) brain damage; or (c) paralysis; or (d) permanent loss of function of any organ or limb; or (e) permanent and disfiguring scarring; or (f) exacerbation of the conditions being treated; or (g) an unusually prolonged period of recovery; or (h) a detrimental change of personality; or (i) a high level of pain and stress
- 7. any treatment involving testing for the HIV virus.

Major treatment does not include treatment administered in the course of a clinical trial.

Consent by the Person Responsible to the carrying out of major medical treatment should generally be given in writing. However, it can be given orally if it is not practicable to do so in writing because of the need to provide treatment quickly. Where treatment proceeds based on oral consent, the consent must later be confirmed in writing using the *Consent – Substitute Consent for Medical Procedure/Treatment* form.

Minor treatment

Minor treatment is any medical or dental treatment which does not fall within the definition of Special Treatment or major medical treatment. Minor treatment does not include treatment administered in the course of a clinical trial.

Consent to minor medical treatment can be given by the Person Responsible. It should generally to be given in writing, but may be given orally if:

- it is not practical to give written consent, and
- the Person Responsible does not require it to be given in writing.

If there is no Person Responsible available or willing to give consent, minor treatment can proceed without consent. In such cases, the Health Practitioner carrying out the minor treatment is required to certify in writing in the patient's Health Record that the treatment is necessary and is the form of treatment that will most successfully promote the patient's health and wellbeing, and the patient does not object to the carrying out of the treatment.

Special Treatment

Special Treatment is defined as:

- 1. any treatment that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out
- 2. any new treatment that has not yet gained the support of a substantial number of Medical Practitioners or dentists specialising in the area of practice concerned, or
- 3. any treatment declared by the regulations to be special treatment for the purposes of the *Guardianship Act*.

The following treatments have been declared by the regulations to be Special Treatment:

- 1. any treatment that is carried out for the purpose of terminating pregnancy,
- 2. any treatment in the nature of a vasectomy or tubal occlusion,
- 3. any treatment that involves the use of an aversive stimulus, whether mechanical, chemical, physical or otherwise.

Special Treatment does not include treatment administered in the course of a clinical trial.

7.8. Who provides substitute consent to Special Treatment?

A Person Responsible cannot provide consent to Special Treatment. Consent to the initial administration of Special Treatment may only be granted by the Guardianship Division of NCAT.

NCAT can only consent to the carrying out of Special Treatment if it is satisfied that the treatment is necessary:

- (a) to save the patient's life, or
- (b) to prevent serious damage to the patient's health.

If the Guardianship Division gives consent to Special Treatment, it can then authorise the guardian to give consent to continuing the treatment or to further treatment of a similar nature.

The *Guardianship Regulation* identifies two categories of Special Treatment for which different criteria apply for obtaining consent from the Guardianship Division:

- 1. any treatment that involves the administration of one or more restricted substances for the purpose of affecting the central nervous system of the patient, but only if the dosage levels, combinations or numbers of restricted substances used, or the duration of the treatment, are outside the accepted mode of treatment for such a patient
- 2. any treatment that involves the use of androgen-reducing medication for the purpose of behavioural control.

The NCAT can only consent to the carrying out of these types of treatment if it is satisfied that the treatment is the only or most appropriate way of treating the patient and is manifestly in the best interests of the patient, and in so far as the National Health and Medical Research Council has prescribed guidelines that are relevant to the carrying out of that treatment—those guidelines have been or will be complied with as regards the patient.

Where there is no existing guardianship order in place for a patient, the Health Practitioner should consider making both an application for guardianship and an application for consent to Special Treatment. The Guardianship Division can give consent to Special Treatment for a duration (for example 12 months) so guardianship may not be necessary in some cases, depending on the circumstances of the patient.

Further guidance

- NCAT Guardianship Division Factsheet Person Responsible
- NCAT Guardianship Division Special medical treatment guidelines

7.9. What if the patient objects to the treatment?

A Person Responsible cannot override a patient's objections to treatment. An objection includes where:

- the person has previously indicated in similar circumstances that he or she did not want the treatment and has not subsequently changed their views, or
- the Person Responsible is aware, or ought reasonably to be aware, that the patient objects to the treatment.

It is an offence under the Guardianship Act for treatment to be carried out if the patient is objecting, unless:

- the Guardianship Division of NCAT has consented to the treatment, or
- the Guardianship Division of NCAT has appointed a guardian with express authority to override the patient's objections and the guardian has provided consent, or
- the patient has minimal or no understanding of what the treatment entails, and the treatment will cause the patient no distress or, if it will cause the patient some distress, the distress is likely to be reasonably tolerable and only transitory.

An application may also be made to the Supreme Court under its *parens patriae* jurisdiction to consent to necessary treatment where the patient is objecting.

Example

Alison is a 30-year-old woman who requires surgery for gallstones. Although Alison has an intellectual disability, she is usually able to consent to her own medical treatments when they are of a minor nature. Currently, her surgeon has assessed Alison as not having the ability to understand the full details of the proposed treatment. Therefore, her mother has consented to the operation as her Person Responsible under the *Guardianship Act*. However, Alison is refusing to have the operation notwithstanding numerous discussions between Alison, her mother, her social worker and the surgeon.

In view of the nature of the medical treatment and the level of Alison's understanding which would be described as greater than 'minimal or no understanding' the exemption under section 46(4) *Guardianship Act* (outlined above) does not apply. In addition, the treatment is significant and is likely to cause more than transitory distress.

The surgeon cannot rely on the consent of Alison's mother as the Person Responsible while Alison is objecting unless Alison's mother is an appointed guardian with a medical and dental consent authority and an additional authority to override Alison's objections. If the mother has not been formally appointed as a guardian with these functions then in order to obtain lawful consent to the operation, an application must be made to the Guardianship Division of NCAT to consent to the surgery and/or to appoint the mother as a guardian with an on-going medical and dental consent authority and additional authority to override Alison's objections.

7.10. What if the treatment is required in an emergency?

Unless there is a valid ACD, treatment may be provided to a person who is unable to consent where the Medical Practitioner carrying out or supervising the treatment considers treatment is necessary as a matter of urgency to save their life, to prevent serious damage to the patient's health, or (except in the case of Special Treatment), to alleviate significant pain or distress. Consent is not required in these circumstances.

7.11. Treatment administered in the course of a clinical trial

A clinical trial is defined in the *Guardianship Act* as 'a trial of drugs or techniques that necessarily involves the carrying out of medical or dental treatment on the participants in the trial'. This includes the administration of placebos to patients.

A person unable to consent may not participate in a clinical trial unless the trial has been approved by the Guardianship Division of the NCAT under the *Guardianship Act*.

In considering an individual patient's participation in such a trial, the Guardianship Division of NCAT will decide whether consent can be granted by either the Person Responsible or whether it should be granted by the Guardianship Division.

Further guidance

NSW Civil and Administrative Tribunal, Guardianship Division, <u>Clinical trials</u>