



Advocacy and decision-making in relation to medical and dental treatment and other health care

Caution

Please note that this document covers complex areas of law. In order to make the document accessible, there have been some simplifications. Please consult your manager or the legal unit for clarification.

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1 Section 1: Introduction and context

1.1 Purposes of practice guideline

The purposes of this practice guideline are:

1. to assist workers on the Advice Service provide accurate information about the legal requirements of consent to medical and dental treatment and other health care to
 - medical, dental and health practitioners
 - competent patients who are considering making enduring powers of attorney (EPA) (medical treatment) and enduring powers of guardianship (EPG)
 - competent patients who are considering making a ‘Refusal of Treatment Certificate: Competent Person’ and common law advance directives
 - substitute decision-makers – guardians, agents, persons responsible
 - family members concerned about decision-making of substitute decision-makers.
2. to assist Advocate/Guardians
 - whose decision-making authority includes the powers and duties to make decisions concerning medical and dental treatment and other health care

- who are involved on an advocacy basis in facilitating communication about the requirements for consent or supporting a person to make a decision
 - who are conducting investigations for Victorian Civil and Administrative Tribunal (VCAT) into the need for a guardian to be appointed to make medical and health care decisions.
3. to support the Office of the Public Advocate’s (OPA) community education program.

1.2 Related practice guidelines

Please note that this practice guideline replaces, and incorporates, the former practice guidelines:

- Consent to medical treatment
- Refusal of medical treatment
- Not for resuscitation.

Other OPA practice guidelines focus on specific issues arising in medical, and related, decision-making. See:

- Jehovah’s Witnesses and blood transfusion
- People with HIV
- Special procedures
- Organ donation
- Medical research
- Mental illness (which includes discussion about non psychiatric medical treatment for persons on involuntary treatment orders).

1.3 The rights of a patient at common law

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body.”¹

The requirements of consent to, and the right of refusal to, medical treatment are complex areas of law and often poorly understood in the general community and even in the health sector. OPA has an important educative role to play in order to safeguard people’s rights.

The common law informs the current statutory regime in Victoria.

The tort (wrong) of trespass to the person consists of:

- assault – fear of a battery
- battery – unlawful touching
- false imprisonment.

There are various defences to a battery; including:

- the person consented to the touching
- necessity (ie medical emergency does not require consent).²

¹ Justice Cardoza in *Schloendorff v Society of New York Hospital*, 211 NY 125, 130 (1914)

² s.42A of the GAA provides that a registered practitioner may carry out, or supervise the carrying out of, a special procedure, a medical research procedure or medical or dental treatment on a patient without consent if the practitioner believes on reasonable grounds that the procedure or treatment is necessary, as a matter of urgency—

(a) to save the patient's life; or

(b) to prevent serious damage to the patient's health; or

Common law principles and the ethical principle of autonomy are concerned with protecting individual bodily integrity, stemming from a right to self-determination. Potentially, the patient's right to autonomy and self-determination can come into conflict with the medical practitioner's interest in saving life, wherever possible. Advocacy for patients with decision-making disabilities involves promoting the patient's rights against paternalistic views. Refer to section 4.2 which details the AMA's Code of Ethics.

1.4 Relevant legislation

The current regime of legislation which has arisen from the common law principles includes:

1.4.1 Guardianship and Administration Act 1986 (GAA)

Part 4A of the GAA provides for the requirements of substitute consent for patients lacking capacity. Note s.42O which provides that medical practitioners who act in compliance with the requirements of the GAA will *not* be

- guilty of assault or battery; or
- guilty of professional misconduct; or
- liable in any civil proceedings for assault or battery.

1.4.2 Mental Health Act 1986 (MHA)

The MHA provides for the requirements of consent and substitute consent for patients on involuntary treatment orders (including those people on community treatment orders) in relation to *non-psychiatric medical treatment*.

1.4.3 Medical Treatment Act 1988 (MTA)

The MTA provides for the appointment of a medical agent who is delegated the right to refuse treatment for a subsequently incapable patient. Refer to sections 5 and 6 for a discussion of common law advance directives.

1.4.4 Charter of Human Rights and Responsibilities Act 2006 (Charter).

The Charter provides that a person must not be:

- (a) subjected to torture; or
- (b) treated or punished in a cruel, inhuman or degrading way; or
- (c) subjected to medical or scientific experimentation or treatment without his or her full, free and informed consent.

OPA is a 'public authority' as defined by the Charter and consequently Advocate/Guardians must ensure their decisions are compliant with the Charter. Likewise, many hospitals and health care providers will be defined 'public authorities' as they have functions of a 'public nature' and must therefore act in accord with the requirements of the Charter.

1.5 OPA – Policy and Principles

The following policy statements and principles should inform the way we do our work. Further information about these matters is provided in the body of this guideline.

(c) in the case of a medical research procedure or medical or dental treatment, to prevent the patient from suffering or continuing to suffer significant pain or distress.

1. The capacity of a patient to make their own medical and health care decisions should be presumed. Capacity should be decision-specific.
2. When a patient has impaired decision-making they should be supported and resourced, as far as possible, to be able to make an informed decision about their medical treatment and health care.
3. The responsibility of assessing capacity sits with the practitioner who is proposing to provide the treatment.
4. If there is a dispute as to the person's capacity, it might be necessary to consider making an application to VCAT for the evidence to be presented and a legal determination made.
5. If a person has a guardian with powers to make decisions concerning medical and dental treatment and other healthcare then the presumption of capacity has been rebutted by VCAT and the guardian must *formally* provide consent in relation to the particular treatment.
6. When VCAT makes an order for medical or dental treatment and health care, there will nearly always be a presenting need or condition about which the guardian needs to make a decision. However, if another medical or health care issue arises during the course of the order, the guardian must also give consent for procedures associated with that condition.
7. All persons with disability have the same entitlement to medical treatment and health care as other members of the community, including preventative health care.
8. A guardian is responsible for ensuring that a person with a disability has access to the same level of health care as someone without a disability, and at the same time is not subjected to procedures which are primarily for social convenience or the benefit of their carers rather than themselves.
9. The s.42K notification process established by the GAA is intended as a less restrictive means, than by the appointment of a guardian, to ensure a person receives treatment and their best interests are promoted. However, on occasion, a person's best interests may not be met, notwithstanding compliance with s.42K of the GAA, in which case consideration should be given to OPA providing advocacy or an application being made for guardianship.
10. Where a patient's ongoing treatment has been deemed as futile and burdensome and not clinically indicated, an Advocate/Guardian should seek an independent second specialist medical opinion.
11. OPA will prioritise advocacy matters which involve facilitating communication between medical and health practitioners and the family members of a patient when there is a dispute about the efficacy of treatment or relevant processes in decision-making where a person is likely to die.
12. Guardians should complete a 'Refusal of Treatment Certificate Agent or Guardian of Incompetent Person' rather than sign 'NFR (not for resuscitation) directives'.

1.6 Notifications to the Public Advocate

The Public Advocate must be kept informed about:

- Decisions made under the MTA to refuse treatment, involving completion of 'Refusal of Treatment Certificate Agent or Guardian of Incompetent Person'.
- Decisions made under the GAA to withhold consent to treatment in which the non-provision of medical treatment is likely to lead to the death of a patient.
- Cases where OPA is providing advocacy in the context of the patient's possible end of life.
- Cases which would be considered a 'reportable death' to the Coroners office.

Advocate/Guardians should complete a Notification to Manager form which is available on *G:Advocate Guardian Program: Notifications*.

2 Section 2: Power to make decisions

2.1 Definition of medical treatment

The GAA, MHA and the MTA all define medical treatment slightly differently and, arguably, are in contradiction. It is therefore important to be clear under which Act the substitute decision-maker is making their decision. See the example at the end of this section which illustrates the difficulties which arise from the different definitions.

OPA has developed a table of what constitutes ‘medical or dental treatment’ for the purposes of the GAA.

It is important to note that under the MTA palliative care is expressly excluded from the definition of medical treatment. It is therefore, *not* possible to refuse palliative care.

The decision of BWV³ states that the provision of *artificial* nutrition and hydration is medical treatment, and therefore it can be refused. It is not possible to refuse the reasonable offer of food and water.

Much health care will not be ‘medical treatment’ within the meaning of the GAA, MTA or the MHA. This does not mean there will not be a need for consent to such treatment but the provisions of these Acts may not apply. This can make it confusing for health practitioners and substitute decision-makers to know what is expected. As stated in section 1.3 unlawful touching can constitute a (civil) assault but consent is a defence. In the case of the GAA only medical or dental treatment provided by registered medical and dental practitioners is covered by the provisions in Part 4A. Therefore, treatment provided by other healthcare practitioners is not captured and they should not seek the consent of a ‘person responsible’ as this has no application.

In the case of treatment not deemed ‘medical or dental treatment’ under the GAA, the relevant medical or dental practitioner may be able to proceed without substitute consent from the person responsible.

Example

- The GAA expressly excludes ‘the administration of a pharmaceutical drug’ from the definition of ‘medical and dental treatment’. Therefore, as indicated above, the relevant medical or dental practitioner may be able to proceed without substitute consent from the person responsible.
- The MTA defines ‘medical treatment’ as including ‘the administration of a drug or other like substance’. Therefore, a medical agent or a guardian may consider exercising their decision-making authority to *refuse* such medical treatment.
- The MHA defines ‘non psychiatric treatment’ as including ‘the administration of any course of treatment or course of medication requiring a prescription or medical supervision’. If the patient who is subject to an involuntary treatment order is incapable of consenting to non psychiatric treatment then the treatment can only be performed with the consent of those persons named in s.85 of the MHA.(see section 2.11).

2.2 Capacity

“The terms competency and capacity are frequently used interchangeably by both health and legal professionals. Strictly speaking, competency refers to the legal concept, while decision-making capacity is assessed by health professionals, with these assessments forming the basis of medical advice and recommendations concerning legal competency.”⁴

³ BWV[2003]VCAT 121 and Gardner; Re BWV [2003] VSC 173

⁴ Ian Freckleton, Kerry Petersen (ed) *Disputes and Dilemmas in Health Law*, Federation Press, 2006, at p.57.

Section 36 of the GAA provides that a 'patient' means a person with a disability who is of or over the age of 18 years and is incapable of giving consent to the carrying out of a special procedure, a medical research procedure or medical or dental treatment.

A person is incapable of giving consent if he or she:

- (a) is incapable of understanding the general nature and effect of the proposed procedure or treatment; or
- (b) is incapable of indicating whether or not he or she consents or does not consent to the carrying out of the proposed procedure or treatment.

It is the medical, or dental, practitioner, who is carrying out the medical, or dental, treatment who needs to ensure they have obtained a full, free and informed consent. The onus is therefore upon them to assess the patient's capacity. This does not have to involve particular assessments; this will depend upon the nature of the procedure. Sometimes, the practitioner will consider there is a need for a specialist assessment from a geriatrician, neuropsychologist, psychiatrist, neurologist, etc.

2.3 Supported decision-making

Advocate/Guardians may have a role in advocating for the right of a person to make their own medical decisions, and to be supported to do so, and challenge any paternalistic views which may be held by family members, service providers and health practitioners. It may be assumed that a person with an intellectual disability, in particular, is incapable of providing consent to *any* medical treatment because their 'next of kin' has always assumed this responsibility.

In circumstances where it appears unclear whether a patient has capacity to consent to a proposed procedure there may be a need for advocacy to the relevant medical practitioners to consider and assess this properly. It should not be assumed a person does not have capacity because it is difficult to assess this. On occasion it may be that a person with appropriate support and resourcing will be able to demonstrate that they have the capacity, within the meaning of s.36 GAA, to make the decision.

If the patient has a guardian to make medical and health care decisions for them but the Advocate/Guardian considers that the patient is capable of making their own decisions and this is supported by evidence, then the Advocate/Guardian should consider applying for a reassessment of the guardianship order. Otherwise the guardian will be required, formally, to provide any consent to recommended treatment. Even if the represented person consents to the procedure it is the guardian's consent which is required and they should sign any consent form.

In many instances consent may be implied. For example, if a physiotherapist is working with a person with dementia and the person is cooperative then consent may be implied from their conduct. Similarly, the consent of a person who holds out their arm in order for an injection or for the taking of blood may be implied from their conduct.

It is important, however, that compliance is not conflated with consent and resistance is not conflated with lack of capacity. The person providing the treatment must be satisfied that the patient appears to understand the general nature and effect of the treatment.

2.4 Decision-making powers of the person responsible

2.4.1 Medical and dental treatment

The 'person responsible' is defined in the GAA. The person responsible therefore has the powers and duties which Part 4A of that Act allows.

The person responsible can consent, or not consent, to 'medical or dental treatment'. Section 38 of the GAA provides that the person responsible must make their decision in the best interests of the patient and does so by taking into account the following matters:

- the wishes of the patient, so far as they can be ascertained
- the wishes of any [nearest relative](#) or any other family members of the patient
- the consequences to the patient if the treatment is not carried out
- any alternative treatment available
- the nature and degree of any significant risks associated with the treatment or any alternative treatment
- whether the treatment to be carried out is only to promote and maintain the health and well-being of the patient.

If the person responsible consents, then the medical or dental treatment can proceed. If anyone considers that the person responsible is not making a decision in the best interests of the patient they could apply to VCAT:

- for the naming of another person as person responsible (s.37(1)(b) GAA)
- for the appointment of a guardian.

If the person responsible does not consent (that is, they *withhold* consent) to the proposed medical or dental treatment but the relevant practitioner nevertheless believes on reasonable grounds that the proposed treatment is in the best interests of the patient then they can complete a s.42M statement. If the person responsible does not apply to VCAT within 7 days of receiving this notice then the practitioner may proceed with the treatment. This is a less restrictive option than an application for guardianship but rarely utilized as it appears applications for guardianship are favoured.

The person responsible needs to be 'reasonably available and willing'. On occasions, a person who could be the person responsible may appear to be unwilling to make a decision. In this situation, it is important to distinguish between whether they are 'reasonably available and willing' to be a decision-maker but contemplating not consenting to the recommended treatment, as opposed to indicating that they are not 'reasonably available and willing' to be a decision-maker. If the latter, then the medical practitioner needs to work down the hierarchy to ascertain the next person eligible for consideration as person responsible. Put another way, there is a difference between ambivalence about being a decision-maker and ambivalence about the decision itself.

When the person responsible withholds consent to treatment the practitioner should not work down the list of other possible persons responsible to find someone who will consent!

A person responsible not consenting to treatment (or withholding consent) is not the same as *refusing* treatment. However, it may have the same effect, if the medical practitioner does not elect to proceed under s.42L of the GAA. Please consult the legal unit if it is unclear whether consent is being withheld or treatment refused.

The person responsible may apply to VCAT (s.42I GAA) for directions or an advisory opinion on any matter or question relating to the scope or exercise of his or her authority to consent to medical or dental treatment on behalf of the patient. If the guardian is the 'person responsible' they can elect to seek advice under this provision, or under s.30 (advice to guardian).

Guardians with powers to make decisions concerning ‘medical or dental treatment’ should be aware that when making decisions under the GAA they are doing so as ‘person responsible’. In the event that the represented person also has a medical agent then the guardian would not be the person responsible unless the medical agent was not willing and available to make a decision.

2.4.2 Medical research procedures

The person responsible can consent, or not consent, to ‘medical research procedures’. Refer to the practice guideline on Medical Research Procedures for further information about this.

2.4.3 Authority conferred by other legislation

The person responsible may have powers conferred by other legislation. For example, the *Health Records Act 2001* includes the person responsible within the list of possible authorized representatives. Also the *Public Health and Wellbeing Act 2008* requires that the person responsible be ‘counseled’ when an incompetent patient, has a blood test taken for HIV or other prescribed disease (s.138(3)(b)).

2.5 Decision-making powers of a medical agent

A medical agent appointed under an Enduring Power of Attorney (Medical Treatment), provided they are reasonably available and willing, will be the person responsible under the GAA as they are the first listed in the hierarchy in s.37 in the GAA.

In addition to any powers and duties they may have as person responsible under the GAA, or as conferred by other legislation to the person responsible, they have the powers set out in the MTA.

Therefore, the options open to a medical agent when they are asked by a practitioner to consent to medical or dental treatment are:

1. consent to the treatment – as person responsible under the GAA
2. not consent, or withhold consent, to the treatment – as person responsible under the GAA
3. refuse the treatment – as agent under the MTA.

In relation to refusal of treatment the agent *must* comply with the conditions in s.5B(2) of the MTA:

“An agent or guardian may only refuse medical treatment on behalf of a patient if-

- (a) the medical treatment would cause unreasonable distress to the patient; or
- (b) there are reasonable grounds for believing that the patient, if competent, and after giving serious consideration to his or her health and well-being, would consider that the medical treatment is unwarranted.”

A ‘Refusal of Treatment Certificate Agent or Guardian of Incompetent Person’ *must* be completed.

It is only possible for a ‘Refusal of Treatment Certificate Agent or Guardian of Incompetent Person’ to be completed when there is a *current* condition. It is not possible to refuse speculative treatment for a speculative condition. See section 6 on end of life decision making for a discussion about common law advance directives.

If the practitioner or any other person considers that the agent, in refusing treatment, is not acting in the best interests of the patient, they can apply to VCAT. Refer to section 7 for discussion of the powers of VCAT.

2.6 Decision-making powers of a guardian appointed by VCAT

When VCAT makes an order for ‘medical or dental treatment or other health care’ there will nearly always be a presenting need or condition about which the guardian needs to make a decision. However, if another health care issue arises during the course of the order, the guardian must also give consent for procedures associated with that condition.

The usual order for the appointment of a guardian with health care powers is expressed in the following terms –

“Except as otherwise provided in Part 4A, to make decisions concerning medical or dental treatment or other health care matters”.

The expression “except as otherwise provided for in Part 4A” is a reference to part 4A of the *GAA*. This refers to three provisos that may prevent the guardian from being the represented person’s decision-maker:

- Where the treatment involves a special procedure, in which case VCAT must provide consent;
- Where the treatment is provided in an emergency; and
- Where the person responsible is someone other than the guardian, in which case that person will have authority to consent to medical and dental treatment.

It is possible, although unlikely, that there will be an operative Enduring Power of Attorney (medical treatment) in place at the same time as a guardianship order. If so, it is the agent (if available and willing) who would be the ‘person responsible’.

It is possible that a guardian was appointed to make decisions for a complex medical decision but that consequently decisions need to be made which the patient is competent to make or that the represented person has now regained capacity. In such circumstances, the guardian formally needs to provide consent but consideration should be given to applying for a reassessment.

If the guardian is the person responsible then they have the powers and duties as explained in section 2.4. In addition to taking into account the matters specified in s.38 of the *GAA* (spelt out in section 2.4) guardians must ensure they comply with the requirements of s.28 of the *GAA*. A guardian acts in the best interests of a represented person if the guardian acts as far as possible-

- as an advocate for the represented person
- in such a way as to encourage the represented person to participate as much as possible in the life of the community
- in such a way as to encourage and assist the represented person to become capable of caring for herself or himself and of making reasonable judgments in respect of matters relating to her or his person
- in such a way as to protect the represented person from neglect, abuse or exploitation
- in consultation with the represented person, taking into account, as far as possible, the wishes of the represented person.

A guardian must also keep in mind the objects of the *GAA* and exercise their powers and duties so that:

- the means which is the least restrictive of a person’s freedom of decision and action as is possible in the circumstances is adopted; and
- the best interests of a person with a disability are promoted; and
- the wishes of a person with a disability are wherever possible given effect to.

If the guardian proposes to refuse treatment under the MTA then the same conditions as for agents must be met.

An Advocate/Guardian should be clear whether they make their decision under the:

- *Guardianship and Administration Act*
- *Medical Treatment Act*
- *Mental Health Act.*

and when documenting their decision, and reasons, indicate the source of their decision-making authority.

As indicated in section 2.4 the person responsible can seek advice in relation to ‘medical or dental treatment’. A guardian (including an enduring guardian) with healthcare powers could also seek under advice under s.30 GAA if it is unclear whether a decision could be described as a ‘health care’ decision and is within the scope of the order.

2.7 Decision-making powers of an enduring guardian appointed by donor

An enduring guardian with power to make decisions concerning medical and dental treatment may be the person responsible. If so, they have the powers and duties as specified in the section 2.4 about the person responsible.

An enduring guardian may have been given power to make decisions concerning health care. If so, they will have the power to consent, or not consent, to health care. The GAA does not define ‘health care’. At OPA we have assumed it to include things such as physiotherapy, mobility assistance, alternative health therapies.

2.8 Special procedures

The GAA provides that only VCAT can provide consent to special procedures. This means:

- any procedure that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out
- termination of pregnancy
- any removal of tissue for the purposes of transplantation to another person.

Refer to the practice guideline on special procedures and the practice guideline on organ donation for a fuller discussion.

If a health service enquires about the need to apply to VCAT for consent to a procedure, such as a hysterectomy, when it is not reasonably likely to have the effect of rendering the person permanently infertile (because they already are permanently infertile) then it would not be a ‘special procedure’ but it would be medical treatment requiring the substitute consent of a person responsible.

2.9 Section 42K

If there is no person responsible, then the treating medical or dental practitioner can complete a s.42K notice and register it with OPA. Contrary to common view, OPA does not approve the treatment or consent to it. OPA’s role is to ensure that the legislative requirements are met. In effect, there is no consent to the treatment. The practitioner recommending the treatment is of the view that it is in the best interests of the patient.

From an advocacy perspective OPA has an important role in monitoring s.42K notices. The following matters should be raised with the advice service coordinator or the legal unit or a manager:

- Instances where a patient appears to have been the subject of multiple s.42K procedures; it may be necessary to consider whether it would be in the best interests of the patient to have a guardian who can make decisions based on the patient's best interests
- If it is not clear whether the treatment is medical or dental treatment within the meaning of the GAA
- If the procedure proposed raises broader concerns than simply a medical assessment of the procedure itself – for example, the lifestyle implications of an amputation or PEG tube feeding.

In circumstances where the patient is to undergo several procedures (for example, a course of chemotherapy or radiotherapy) it should suffice for the medical practitioner to register a single s.42K notice, rather than a s.42K notice in respect of each individual procedure.

2.10 Section 42T

Medical research procedures, formerly, were defined as a 'special procedure'. However, there is now the same process for providing substitute consent to medical research procedures as for medical or dental treatment. A person responsible can provide consent. If there is no person responsible, the practitioner conducting the research can comply with the procedural authorization steps detailed in s.42T of the GAA and provide a certificate to OPA.

Refer to the practice guideline on medical research procedures for a fuller discussion.

2.11 Involuntary treatment orders

The person responsible provisions of the GAA do not apply to persons on involuntary treatment orders (including people on community treatment orders). The MHA provides a different hierarchy of possible substitute decision-makers for patients, over the age of 18, who are unable to provide informed consent to non-psychiatric medical treatment (see s.85).

- Medical agent appointed under an Enduring Power of Attorney (Medical Treatment)
- Person appointed by VCAT to make decisions concerning the proposed treatment
- A guardian with power to make decisions concerning the proposed treatment
- An enduring guardian appointed under an Enduring Power of Guardianship with power to make decisions concerning the proposed treatment
- The authorized psychiatrist.

If an application is made for a guardian for the sole purpose of making a decision concerning proposed non-psychiatric medical treatment the Advocate/Guardian investigating such application should explore why it is not possible for the authorized psychiatrist to consent, as this would be less restrictive than the appointment of a guardian.

2.12 What does the decision-maker need to know?

A doctor will make a clinical assessment of a patient's condition and make recommendations for treatment. A competent patient will consider those recommendations and make a decision they consider in their own best interests, having regard to a range of (medical and non-medical) factors. A substitute decision-maker, similarly, when considering whether to consent to, or withhold consent to, or refuse treatment for a patient with impaired decision-making needs to get to know the patient so they can make a decision in their best interests.

As described in section 2.4, the person responsible must comply with s.4 (objects of the Act) and with s.38 (best interests) of the GAA and the guardian must also comply with s.28 (exercise of authority of the guardian) of the GAA and if an agent or guardian is refusing treatment they must comply with s5B(2) of the MTA.

The decision-maker may need to ask additional questions, for example:

- is the purpose of the procedure: to cure, relieve symptoms, or to investigate further?
- what are the benefits of the proposed treatment or procedure?
- is the procedure wholly therapeutic?
- would the health care professional recommend the same procedure if the person did not have a disability?
- are there any additional risks to the represented person associated with their disability?
- what are the long or short-term side effects?
- has the specialist advised the patient of the procedure and consulted with the GP and the patient's family?

2.13 Second opinions

Part of the advocacy that might be required is to seek a second opinion either:

- to obtain another view as to the recommended treatment
- or in circumstances where treatment is not being offered.

Advocate/Guardians should consider when it is appropriate to seek a second opinion from a practitioner who is independent of the particular health service which is providing (or not offering) treatment.

2.14 Restraint

In some cases it may be necessary for a patient to be restrained in order to provide them with treatment, or during the recuperative phase. Restraint may consist of:

- chemical restraint
- physical restraint
- environmental restraints, such as specialising (constant patient observation).

The person responsible should be advised of what restraint may be necessary as this would be a relevant factor in determining whether the treatment is in the best interests of the patient. We suggest it is not that the person responsible consent to the restraint, as distinct to the medical treatment, but that it is understood that the restraint is part of the medical treatment.

OPA is giving further consideration to issues relating to the use of restraint. Advocate/Guardians should consult the Legal Unit for advice if a request is made to them to consent to restraint, particularly in the context when restraint is not for therapeutic purposes but for behavioural management.

2.15 Discharge Planning

After a procedure, a guardian should follow up with the case manager, hospital and/or treating doctor to ensure that there is good follow through, good discharge planning and full information to the general practitioner and the carers. An Advocate/Guardian should request a copy of the discharge plan.

It is understood that hospitals are under significant pressure for patients to be discharged as soon as they are medically stabilized. However, a guardian may be unable to consent to discharge until there is a

suitable accommodation option. A hospital worker may argue that they cannot keep a person in hospital in these circumstances. In these circumstances, an Advocate/Guardian should liaise with their team leader or the legal unit for advice.

2.16 Weighing up information in decision-making

Clearly, substitute decision-makers must consult with the patient to try to ascertain their wishes, and as far as possible, give effect to them.

The wishes of the patient might be ascertained by:

- Currently expressed wishes expressly communicated by the patient to the substitute decision-maker
- Evidence of past expression of wishes
 - written directives
 - prior decisions made about similar treatment when competent
- Wishes of the patient as reported to the substitute decision-maker by interested parties
 - reports of discussions in which the patient had expressed their views about particular treatment
 - the interested party's projected views about what the patient would want based on their knowledge of the patient
- Wishes of the patient as understood and interpreted by the substitute decision-maker (eg non verbal communication).

Substitute decision-makers should also consult with all relevant medical and health care practitioners and with family and others who have a particular interest in the welfare of the patient.

In more complex matters, Advocate/Guardians are encouraged to seek supervision from their team leader or manager.

It is important to recognise that working out a person's best interest requires a proper and careful assessment of all relevant factors on every occasion.

2.17 Writing up reasons for decision

Advocate/Guardians should document *all* medical and health care decisions. The decision should be described and the source of decision-making noted. In general, it will also be necessary to document the reasons for the decision.

2.18 Communication of the decision

Once a decision is made then the patient should be advised. It may also be necessary, post the procedure, to meet with the patient, particularly if they have recovered capacity, and explain the decision made and the reasons for it.

In general, the primary carer should be advised of the decision; particularly, if they are involved in day to day care. Discretion should be exercised as to whether to communicate decisions to other persons. Represented persons have a right to privacy. It may not be necessary for others to be advised of medical conditions or treatment.

Note that Health Privacy Principle 2.4 in the *Health Records Act 2001* provides that health information *may* be disclosed to an individual to an immediate family member if the disclosure is necessary to provide appropriate health services or care of the individual or the disclosure is made for compassionate reasons.

2.19 Particular medical issues

Some medical procedures raise particular issues for consideration.

Refer to section 6 for discussion about ‘no Cardio Pulmonary Resuscitation (CPR) orders’.

3 Section 3: Minors

3.1 Decision-making authority in relation to medical treatment for minors

Although a guardian cannot be appointed for a person under the age of 18 years, OPA often receives calls on the Advice Service about who can consent for minors (whether they have a disability or not) to medical treatment.

Unless orders have been made by a Court to the contrary (usually the Family Court of Australia or the Children’s Court) it will be a child’s parents who will be able to provide consent to medical treatment.

If parents, or other interested parties, are in conflict then they may elect to apply under the *Family Law Act 1975* for orders specifying who is able to make particular decisions.

If a child is deemed in need of protection under the *Children Youth and Families Act 2006* and Guardianship to the Secretary orders have been made then the Secretary to DHS (or delegate) would have the authority to make medical decisions.

3.2 Mature Minor

A medical practitioner should assess a child’s capacity to provide consent. A ‘mature minor’ can provide consent themselves. This is a matter for the practitioner to assess.

3.3 Special medical procedures

Some types of medical decisions are considered not to fall within the realm of parental decision-making and require a Court exercising *parens patriae* jurisdiction to provide consent.

These decisions are those that involve:

- grave consequences that would result for the child from an incorrect decision
- the significant risk of making the wrong decision as to whether such a procedure would be in the child’s best interests.

The rights and well-being of the child in these circumstances are considered so important that there should be greater than usual accountability and that the decision should be made by an objective, independent umpire (ie the Family Court).

Special medical procedures include:

- Difficult ethical issues; for example
 - treatment in relation to gender dysphoria
- Irreversible procedures; for example
 - hysterectomy and tubal ligation
 - vasectomy

- donation of regenerative tissue
- Life threatening situations
- Treatments of significant risk
- Disputed treatments.

See *A Question of Right Treatment: The Family Court and Special Medical Procedures for Children 1998* (available at www.familycourt.gov.au). In this publication, it states that OPA may provide the following information and assistance:

- information, advice and referral options about all alternatives for fertility and/or menstrual management of a child
- information on and assistance in obtaining reports on experts working with children with disabilities
- referral to services to help parents and carers with day to day care of the child
- assistance to identify issues and resolve problems.

Consent to non psychiatric medical treatment for minors is covered by the MHA.

The first of the persons listed below who, in the circumstances, is reasonably available, willing and able to make a decision concerning the proposed treatment, can provide substitute consent:

- a person with parental responsibility (within the meaning of the *Family Law Act 1975*) for the patient;
- a guardian of the patient appointed under a law of the Commonwealth or of a State or Territory;
- a person who, under section 597 of the *Children, Youth and Families Act 2005*, can consent to the performance of the proposed treatment on the patient;
- the authorized psychiatrist if there is no person with parental responsibility, guardian or custodian who is reasonably available, willing and able to make decisions concerning the proposed treatment.

Apart from the special medical procedures matters at the Family Court, on occasions OPA will be involved on an advocacy basis for minors in relation to medical treatment and health care issues. However, the child would need to have a disability.

In addition to *A Question of Right Treatment: The Family Court and Special Medical Procedures for Children 1998* refer to the Family Court's Practice Direction No. 9 of 2004 - Victorian and Queensland Registries: Medical Procedure Applications.

3.4 Termination of pregnancy

It is noted that termination of pregnancy is not specifically mentioned as a special medical procedure in the publication *A Question of Right Treatment: The Family Court and Special Medical Procedures for Children 1998*. However, in 2008 in QLD, the Supreme Court exercising its *parens patriae* jurisdiction did provide consent for a 12 year old child to be administered a pharmaceutical with the intention of inducing miscarriage⁵. Wilson J stated that:

"The Court in its role as *parens patriae* must act in the best interests of the child, B, whereas her parents may ultimately make a decision which favours other and possibly conflicting interests of the family as a whole."

- and -

"in my view this is one of those cases where B is incapable of giving informed consent to the termination of her pregnancy and it is beyond her parents' powers to do so."

1.1 ⁵ State of Queensland v B [2008] QSC 231

It is OPA's policy that if a minor is deemed not capable of providing consent to a termination of pregnancy then an application should be made to the Family Court of Australia.

4 Section 4: Working with doctors and health systems

4.1 Duties of doctors

Doctors have a range of duties towards patients, including:

- Protect life
- Not cause inhuman or degrading treatment
- Exercise skill
- Provide information so that the patient can provide full, free and informed consent to treatment, or exercise their right to refuse treatment
- Confidentiality.

4.2 Doctor – patient relationship

The AMA Code of Ethics covers the following topics:

- The Doctor and the Patient (Patient Care, Clinical Research, Clinical Teaching, The Dying Patient, Transplantation)
- The Doctor and the Profession (Professional Conduct, Advertising, Referral to Colleagues)
- Professional Independence
- The Doctor and Society

In relation to patient care it provides as follows:

- (a) Consider first the well-being of your patient.
- (b) Treat your patient with compassion and respect.
- (c) Approach health care as a collaboration between doctor and patient.
- (d) Practise the science and art of medicine to the best of your ability.
- (e) Continue lifelong self-education to improve your standard of medical care.
- (f) Maintain accurate contemporaneous clinical records.
- (g) Ensure that doctors and other health professionals upon whom you call to assist in the care of your patients are appropriately qualified.
- (h) Make sure that you do not exploit your patient for any reason.
- (i) Avoid engaging in sexual activity with your patient.
- (j) Refrain from denying treatment to your patient because of a judgment based on discrimination.
- (k) Respect your patient's right to choose their doctor freely, to accept or reject advice and to make their own decisions about treatment or procedures.
- (l) Maintain your patient's confidentiality. Exceptions to this must be taken very seriously. They may include where there is a serious risk to the patient or another person, where required by law, where part of approved research, or where there are overwhelming societal interests.
- (m) Upon request by your patient, make available to another doctor a report of your findings and treatment.
- (n) Recognise that an established therapeutic relationship between doctor and patient must be respected.
- (o) Having initiated care in an emergency setting, continue to provide that care until your services are no longer required.
- (p) When a personal moral judgment or religious belief alone prevents you from recommending some form of therapy, inform your patient so that they may seek care elsewhere.

- (q) Recognise that you may decline to enter into a therapeutic relationship where an alternative health care provider is available, and the situation is not an emergency one.
- (r) Recognise that you may decline to continue a therapeutic relationship. Under such circumstances, you can discontinue the relationship only if an alternative health care provider is available and the situation is not an emergency one. You must inform your patient so that they may seek care elsewhere.
- (s) Recognise your professional limitations and be prepared to refer as appropriate.
- (t) Place an appropriate value on your services when determining any fee. Consider the time, skill, and experience involved in the performance of those services together with any special circumstances.
- (u) Ensure that your patient is aware of your fees where possible. Encourage open discussion of health care costs.
- (v) When referring your patient to institutions or services in which you have a direct financial interest, provide full disclosure of such interest.
- (w) If you work in a practice or institution, place your professional duties and responsibilities to your patients above the commercial interests of the owners or others who work within these practices.
- (x) Ensure security of storage, access and utilisation of patient information.
- (y) Protect the right of doctors to prescribe, and any patient to receive, any new treatment, the demonstrated safety and efficacy of which offer hope of saving life, re-establishing health or alleviating suffering. In all such cases, fully inform the patient about the treatment, including the new or unorthodox nature of the treatment, where applicable.

4.3 Duty to disclose

In relation to providing information, doctors must:

- provide information about the broad nature and effects of treatment; and
- inform the patient about any ‘material risks’ involved in treatment.

A material risk is defined as “a risk that a reasonable person in the patient’s position, if warned of the risk, would be likely to attach significance to, or ...those risks that a... medical practitioner is, or should reasonably be, aware that the particular patient, if warned of the risk, would be likely to attach significance to”.⁶

Clearly, when there is a substitute decision-maker the duty to inform is directed towards that person. Due to the busyness of medical practitioners, it can sometimes be difficult to speak to the person who is actually providing treatment. It may be that a junior doctor seeks the consent of the patient or their substitute decision-maker. Advocate/Guardians should insist upon speaking to the doctor actually performing the procedure. It is arguable that the duty to inform will not be satisfied by delegating these responsibilities (since the junior doctor may not actually have examined the patient or be aware of the specific risks to the patient).

It is noted that the Medical Practitioners Board in their Medico-Legal Guidelines state:

“Nor is it acceptable to delegate the task of providing information to others ... without input from the practitioner. Doctors are responsible for taking reasonable measures to assure themselves that their patients understand the general nature of the treatment proposed, the options for other forms of treatment, or non-treatment, and the potential consequences of any treatment decision.”

⁶ Rogers v Whittaker 1992 HCA 58

4.4 Clinical assessments of futility of treatment versus judgments about the patient's quality of life

As indicated above, the AMA code of ethics includes “refrain from denying treatment to your patient because of a judgment based on discrimination.”

OPA has an important role to advocate for people with disabilities to ensure that doctors comply with their ethical, and legal, obligations.

If it appears that medical treatment is not being offered because of some judgment about the meaning of a person's disability then this must be challenged.

For example: A doctor indicates that ordinarily for a person with renal failure they would offer dialysis but they will not offer it to this patient because they have an intellectual impairment. Our advocacy would be to explore whether the patient is being unlawfully discriminated against or whether there is some genuine relevance of the patient's intellectual impairment that means that clinically the treatment is considered futile or burdensome.

4.5 How health services work

Health services are complex institutions and sometimes the processes and systems of efficiencies may not be sufficiently flexible to accommodate the needs of patients with impaired decision-making.

For example, a health service may require the completion of a form which the person is not able to complete or sign. It may not be required by law that the form is completed or signed but it becomes a barrier to the provision of the service. Advocate/Guardians have an important role to play in challenging systems which do not accommodate the needs of people with disabilities.

As indicated above, it may be difficult to make contact with the relevant practitioner since communication to obtain consent has been delegated to a junior doctor.

It may be necessary to advocate for a service to allow more time for patients who have disabilities in order to assess properly their capacity to provide consent or to support them to be able to do so.

In hospitals there will be a multi-disciplinary approach. Advocate/Guardians will need to assess which members of a team they need to consult with and to be aware that whilst a team may make a collective recommendation that the assessments of the relevant individuals should also be considered carefully.

4.6 Refusal to provide treatment

There may be occasions when medical treatment is proposed and the Advocate/Guardian consents to treatment but due to the resistiveness of the patient the medical practitioner, on ethical grounds, then refuses to provide the treatment. In such circumstances, Advocate/Guardians should consult with their team leader and the legal unit.

5 Section 5: Health care planning

5.1 Guardian's responsibilities

Advocate/Guardians have a responsibility to ensure health care planning for represented persons and not only provide the reactive function of consenting (or not) to proposed medical treatment. Ideally an annual medical and dental examination should be arranged.

A guardian has a duty to know the general health conditions of a represented person and to monitor these conditions.

Therefore, Advocate/Guardians should ensure the following:

- that the represented person has a general practitioner (GP)
- advise that GP of their involvement
- write to the GP on an annual basis

The guardian's role should focus on decision-making regarding medical treatment. Family and/or primary carers will normally be responsible for routine health care and health care monitoring. They should bring any matters requiring informed consent to the attention of the guardian.

Family and/or carers will usually accompany the represented person to medical appointments. In order to make decisions about the represented person's health care or an operative procedure, the guardian *may* choose to attend medical appointments with the person and/or consult their treating doctors.

A guardian may request further assessments and a second opinion when s/he believes this would benefit the represented person, but it is usually the responsibility of the case manager or primary carer to arrange these.

5.2 Advance care planning

In addition to, or instead of, an Enduring Power of Attorney (medical treatment) a person may wish to document their wishes about future care and treatment. We recommend that callers to our Advice Service be referred to the Respecting Patient Choices website for further information about this.

(www.respectingpatientchoices.org.au).

If a person made an advance directive prior to the appointment of the guardian the guardian should ascertain:

- the competence of the person at the time of making the directive (if possible);
- the circumstances in which the person made the directive;
- whether the person later withdrew the directive or acted contrary to it;
- the current wishes of the person regarding any directive.

The guardian is not bound to follow a directive made by a competent person prior to the guardian's appointment. However, the directive will be relevant to the guardian when determining what is in the represented person's best interests.

5.3 Terminal Care Wishes

Some people will have engaged in a process of documenting their wishes in relation to medical treatment for a current condition or speculatively about future conditions. However, most have not. The way in which this issue presents most commonly for OPA is when a represented person resides in a residential

aged care facility (whether by guardian decision or otherwise) and the facility requires the guardian to complete a terminal care wishes form.

It is presumed, in the absence of a guardian, that the resident themselves or a family member, on their behalf, has completed one of these forms. This raises a number of concerns:

- the person completing the form may not understand what it is they are agreeing to
- the person completing the form may not have the relevant authority to be treated as a substitute decision-maker
- the forms do not comply with the requirements of the MTA (Refusal of Treatment Certificates)
- it is not clear how the forms are stored or used or updated.

If a guardian is asked to complete such a form, it is recommended that they request a meeting be convened with the represented person, family members, the treating GP and the clinical care coordinator of the facility. At such meeting:

- the guardian should explain their decision-making authority and the requirements for any refusal of treatment
- the treating GP and clinical care coordinator should explain the meaning of treatment such as no CPR or tube feeding, etc
- the wishes of the represented person should be elicited and documented
- the wishes of family members should be elicited and documented.

The outcomes from such a meeting might be

- the treating medical practitioner considers it appropriate to make a no CPR order; or
- the guardian considers there is a need to arrange completion of a 'Refusal of Treatment Certificate Agent or Guardian of Incompetent Person'.

Advocate/Guardians may wish to recommend to aged care facilities that they participate in the Respecting Patient Choices program or request our office to provide a professional development session on these issues.

It is noted that guardians who do not have health care powers will also be asked to sign these forms. It is a matter of discretion whether the Advocate/Guardian should try to facilitate a meeting as described above. A guardian has a duty to advocate for a represented person.

6 Section 6: End of life decision-making

6.1 Death

Understandably, people can be very distressed when a family member or friend is dying and if there is disagreement about the best course of action, there is significant potential for conflict and misunderstanding. People will carry feelings of guilt for many years over their perceived role in a loved one's death and it is important to ensure a good death for the patient, as well as a good process for the family.

It is important to be clear about what is lawful and what is consistent with principles of good medical practice and to be clear about roles and responsibilities. This may assist with managing conflict.

The use of language in relation to the relationship between medical care and death is particularly important because of the intensity of feelings people attach to words and concepts such as euthanasia, suicide, 'doctors playing God', dying with dignity, etc.

Physician assisted death, to ensure a ‘good’ death is not lawful.

It is possible for a guardian or medical agent to refuse treatment in the full knowledge that without medical intervention the patient will die. The patient dies of the injury, disease or illness.

Unfortunately, frequently family members are asked to determine whether the patient is ‘NFR’. This is inappropriate and unfair to family members who may carry feelings of responsibility and guilt associated with the decision they assume they are being asked to make. Our office can play an important role in clarifying roles and responsibilities and make clear where the responsibilities for decisions lie:

The AMA Code of Ethics in relation to the dying patient states:

- Remember the obligation to preserve life, but, where death is deemed to be imminent and where curative or life-prolonging treatment appears to be futile, try to ensure that death occurs with dignity and comfort.
- Respect the patient’s autonomy regarding the management of their medical condition including the refusal of treatment.
- Respect the right of a severely and terminally ill patient to receive treatment for pain and suffering, even when such therapy may shorten a patient’s life.
- Recognise the need for physical, psychological, emotional, and spiritual support for the patient, the family and other carers not only during the life of the patient, but also after their death.

6.2 Futile or burdensome treatment

A doctor is not required to provide treatment which is futile and burdensome. This does not only arise in the context of end of life decision-making but it is where OPA will most commonly deal with it.

The AMA has a policy on the role of the practitioner in end of life care:

(<http://www.ama.com.au/node/2803>). In this document the AMA defines futile treatment as:

“Treatment is futile when it is no longer providing a benefit to a patient, or the burdens of providing the treatment outweigh the benefits.”

A doctor may make a clinical decision not to offer treatment, or to withdraw treatment. In such circumstances, a competent patient or in the case of an incompetent patient, a third party may advocate for treatment to be provided. An Advocate/Guardian should consider the need to obtain a second opinion.

If the treatment the doctor considers to be futile or burdensome is *resuscitation* then they can make a ‘no CPR (cardio-pulmonary resuscitation) order’. In effect, in advance, the doctor is indicating that to attempt resuscitation would be unduly burdensome or futile, given the patient’s prognosis. Since treatment is not being offered, there is no need for a ‘person responsible’ under the GAA or a guardian or agent under the MTA to make a decision; they do not need to endorse such clinical decision. It is important that doctors discuss with the patient, the guardian and family members when they make such orders.

6.3 Request for third person to make a NFR decision

Family members, and guardians, are often asked to make NFR (not for resuscitation) decisions when there is no need for them to do so and no authority to do so. Advocate/Guardians can play a key role in liaising with health professionals and patients and families to clarify roles and responsibilities and processes.

As indicated above, a doctor may indicate that to use CPR on a patient would be futile or burdensome and that if the patient has a heart attack which could lead to cardiac arrest then attempts will not be made to resuscitate them, although other treatment could be offered (pain relief, oxygen, and comfort).

However, if it is not indicated that resuscitation would be futile or burdensome then it can be anticipated that if the patient has a cardiac arrest then attempts will be made to resuscitate them. In this situation, it may be necessary to consider whether a substitute decision-maker should refuse such treatment. As discussed in section 2.5 and 2.6, only agents and guardians with authority under the MTA can *refuse* treatment. A 'Refusal of Treatment Certificate' can only be completed in relation to a *current* condition.

There is no common law basis for third parties to refuse treatment for the patient. Therefore, the only basis on which treatment can be refused is subject to the provisions of the MTA.

However, family members may have indicated to health professionals and carers that the patient is 'NFR' either because they think that is what the patient would indicate if competent or because they do not want the patient to have the treatment (whether from benevolent or malevolent motivation). Such directions have no legal status.

6.4 Emergency services

Generally, the issue of resuscitation will be in the context of an emergency and consent is not required. However, if there is a valid 'Refusal of Treatment certificate' in place then treatment cannot be provided even in an emergency.

Paramedics with ambulance services understand that their duty of care is to attempt resuscitation.

Similarly, DHS policy mandates resuscitation for residents in residential services.

DHS have a publication titled "Disability Residential Services Palliative Care guide: End-of-life care for residents of disability residential services".

If there is a concern about resuscitation being provided in these types of circumstances then:

- a competent patient should consider completing a 'Refusal of Treatment Certificate Competent Person'
- an agent or guardian for an incompetent patient should consider completing a 'Refusal of Treatment Certificate Agent or Guardian of Incompetent Person'
- a medical practitioner should be consulted about making a 'no CPR order'.

6.5 Competent patient expresses wish to be NFR

A competent patient who does not want particular treatment, including resuscitation, for a current condition should be encouraged to complete a 'Refusal of Treatment Certificate' under the MTA or appoint a medical agent who would have the power to refuse treatment should the patient lose capacity.

In circumstances where a person when competent, indicated in some way (verbally or in writing in some format) that they did not want particular treatment, including to be resuscitated, then this will be a *common law* advance directive.

In Victoria, it would seem to be that the common law regarding advance directives will be respected. However, once a person is defined as incompetent, their advance directive holds a much weaker position.

For Advocate/Guardians the existence of documented wishes will be very helpful in forming a view about whether to refuse treatment and complete a 'Refusal of Treatment Certificate Incompetent Patient'.

6.6 Request for guardian to make a NFR directive

As should be already clear, a guardian should not be making a 'NFR directive'. When asked to do so by a medical professional it is important to clarify if what they are really saying is that treatment is futile/burdensome and clinically not indicated. If so, it is probably a case of them seeking the guardian's endorsement of their clinical decision. The guardian has no responsibility to endorse their decision but they do have an obligation to advocate for the represented person to ensure the person is not subject to unlawful discrimination and, if relevant, advocate for a second opinion.

As indicated in section 5 Advocate/Guardians are often asked to complete terminal care wishes for residents in aged care facilities. These forms often contain a 'NFR directive'. Further, the forms are often expressed ambiguously and can be difficult to interpret:

For example: -

"In the event of a cardiac arrest or other medical emergency, I do/do not want...to be resuscitated or medically treated in any way..."

The expression "other medical emergency" is not specific and it is unclear what the patient means by it. Further, the expression "or medically treated in any way" is so all-encompassing that a patient would have to conceive of an infinite array of possibilities that could arise in their treatment for them to have the competence to sign such a directive. 'NFR directives' of this kind should not be signed or accepted.

6.7 Summary

1. Doctors have a duty to save life. Treatment should be offered unless it has been clinically assessed as futile or burdensome.
2. If a doctor considers, from a clinical perspective, that CPR would be futile or burdensome then they can make a 'no CPR order'.
3. Competent patients have the right at common law, and codified in the MTA, to refuse medical treatment. If a 'Refusal of Treatment Certificate Competent Patient' has been completed then it must be respected, even in an emergency.
4. If there is no 'Refusal of Treatment Certificate Competent Patient' but there is a common law advance directive then the medical practitioner may elect to respect it, but the practice in relation to common law advance directives will be variable.
5. Even if there is doubt about the status of common law advance directives from a competent patient it is absolutely clear that a third party cannot make a common law advance directive for a patient.
6. However, the wishes of family members are relevant considerations for an agent or guardian who is considering exercising their powers under the MTA.
7. If the patient is not competent and there is no 'Refusal of Treatment Certificate Competent Patient' then only a medical agent or guardian can refuse treatment and they must comply with the

requirements of the MTA and complete a 'Refusal of Treatment Certificate Agent or Guardian of Incompetent Person'.

8. Advocate/Guardians have an important role to play in facilitating end of life planning but should not sign terminal care wishes forms or advance care directives.

7 Section 7: Courts and Tribunals

7.1 VCAT jurisdiction, pursuant to the GAA

VCAT has the power under the GAA to do the following:

- appoint a guardian (with powers and duties to make decisions concerning medical and dental treatment and other health care)
- provide advice to a guardian or an enduring guardian or a person responsible
- appoint a person to be the person responsible
- consent to a special procedure
- in relation to applications made pursuant to s.42N (that is, applications may be made in relation to any matter, question or dispute relating to medical or dental treatment or relating to the best interests of a patient), including:
 - may revoke, suspend or vary an Enduring Power of Guardianship
 - may make an order that any proposed medical or dental treatment is or is not in the best interests of the patient
 - may make any orders or give any directions it considers necessary to resolve any conflict between persons relating to the best interests of a patient
 - may make a declaration as to the validity or effect of any decision relating to medical or dental treatment
 - may give an advisory opinion in relation to the best interests of a patient
 - may make any other orders it considers to be in the best interests of the patient.

7.2 VCAT jurisdiction, pursuant to the MTA

VCAT has the power under the MTA to do the following:

- VCAT may suspend an EPA(MT) if satisfied that the refusal of medical treatment is not in the best interests of the donor.
- VCAT may revoke an EPA(MT) if satisfied that it is not in the best interests of the donor for the power to continue.
- VCAT may revoke or suspend an EPA(MT) as it relates to an alternate agent if the conditions permitting an alternate agent to make decisions have not been met.
- VCAT may revoke or suspend an EPA(MT) if satisfied that the agent and alternate agent have made conflicting decisions about medical treatment and can also determine that any decisions are ineffective and make any decision necessary to resolve the conflict.

7.3 Courts

The following Courts may be involved in disputes concerning medical decision-making:

- Supreme Court dealing with appeals on questions of law from VCAT
- Supreme Court exercising *parens patriae* jurisdiction
- Family Court exercising jurisdiction in relation to special medical procedures for minors.

At times parties may issue proceedings in the Supreme Court for various reasons including:

- An injunction to restrain a procedure being carried out

- A declaration that treatment be provided.

8 Section 8: Health Information and Privacy

8.1 Relevance

OPA holds a lot of personal information and health information about people and must comply with relevant legislation and information/health privacy principles.

We need to think about the information we collect and how it is recorded. This includes:

- collecting existing health information, such as medical reports or other reports which include health information, or noting health information provided during discussions with other workers/interested parties; and
- health information we ask to be created, such as assessments of capacity.

We need to think about how we use health information and how, and if, and to whom, we can disclose it.

We need to think about the authority we have to access health information.

8.2 Legislation

1. *Freedom of Information Act 1982* (FOI Act). OPA is currently exempt under this Act; this means that we can refuse to provide documents requested under this Act. Advocate/Guardians may make FOI requests of other public sector organisations.
2. The *Information Privacy Act 2000* (IPA) covers *personal information* held by state government agencies and local councils.
3. The *Health Records Act 2001* (HRA) covers *health information* in the public and private sectors in Victoria.
4. The *Privacy Act (Commonwealth)* covers federal government agencies and parts of the private sector.
5. *Charter of Human Rights and Responsibilities Act 2006*. The Charter provides for a right to privacy.

HPP and IPP

IPP = information privacy principles

HPP = health privacy principles

8.3 Authorised Representative

HRA – s.85

IPA – s. 64

If the HRA/IPA requires the consent of an individual to the collection, use or disclosure of health/private information, the power to give that consent may be exercised on behalf of an individual who is incapable of giving consent by an authorised representative of that individual.

An authorised representative is defined as:

- (a) a guardian of the individual; or
- (b) an attorney for the individual under an enduring power of attorney; or
- (c) an agent for the individual within the meaning of the *MTA*; or
- (d) an administrator or a person responsible within the meaning of the *GAA*; or
- (e) a parent of an individual, if the individual is a child; or

(f) otherwise empowered under law to perform any functions or duties or exercise powers as an agent of or in the best interests of the individual.

8.4 What is 'health information'?

Health information includes information or an opinion about:

- the physical, mental or psychological health (at any time) of an individual
- a disability (at any time) of an individual
- an individual's expressed wishes about the future provision of health services.

8.5 What is 'personal information'?

Personal information means information or an opinion about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion.

8.6 Collection

We collect health and personal information in the following circumstances:

- when VCAT requests that we conduct an investigation and provides us with the application and supporting material
- when we *require* health and personal information to be provided from “a person, government department, public authority, service provider, institution or welfare organisation” when we conduct an investigation
- when VCAT appoints the Public Advocate as guardian and provides us with the application and supporting material
- when we act as guardian or advocate for a person with a disability
- when we record details from calls to the Advice Service.

We should only collect information that is necessary for our function. Sometimes, people may provide us with information in relation to a person but it is not clear whether we need this information to perform our function. If in doubt, seek legal advice.

8.7 Disclosure

People may seek copies of health and personal information we hold on file. This could be for a range of reasons, including:

- The person with the disability might want a copy of the information.
- A medical expert may request copies of prior assessments in order to inform their own assessment.
- Lawyers for the person with the disability may want to use the information for another legal purpose – such as in defending criminal charges.
- An interested party may want information to pursue matters they consider in the best interests of the person with the disability or to progress matters in their own interests.

Consider whether the person seeking the information could obtain it elsewhere. For example, they may be able to obtain the information from VCAT, or directly from the author of a medical report. **Is it in the best interests of the person with the disability for us to disclose the information?** If in doubt as to whether you can, or must, release such information, seek legal advice.

8.8 Requests for health and personal information made under the FOI Act

Currently, OPA is FOI exempt. If someone makes an application for information pursuant to the *FOI Act*, please consult with the Legal Unit.

Although we are currently exempt, it does not mean that we will not provide information if we consider it to be in the best interests of the person with the disability.

8.9 Access

We may need to access health/personal information about a person with a disability:

- during the course of an investigation
- when acting as guardian in order to obtain information considered relevant to determining what is in the person's best interests
- when providing advocacy in order to obtain information considered relevant to determining what is in the person's best interests.

8.9.1 Investigations referred by VCAT

s.16(1)(ha) *GAA* provides that when VCAT has referred a matter for investigation to OPA pursuant to clauses 35/42/48 of schedule 1 of the *VCAT Act* that we can require a person, government department, public authority, service provider, institution or welfare organisation to provide information.

It would not be a breach of the health privacy principles (see HPP 2.2.c) for health information to be released to OPA pursuant to a VCAT investigation: "the use or disclosure is required, authorised or permitted, whether expressly or impliedly, by or under law..."

8.9.2 Guardians requiring healthcare information to make a healthcare decision

Guardians may wish to access health information specifically to assist with making a healthcare decision and in this circumstance the health service should provide the health information to the guardian in order that they might make an informed decision. This is analogous to the competent patient who would require information disclosure to make an informed decision.

This is consistent with HPP 2.1.

8.9.3 Guardians requiring healthcare information for other purposes

A guardian may seek access to healthcare information for a purpose other than requiring information disclosure to ensure they make an informed decision in relation to health care or medical treatment. If so, access to information is regulated by both the *HRA* and *FOIA*.

The *HRA* gives individuals access to health information about them held in the *private* sector, whereas the *FOI Act* gives individuals access to health information about them held by the *public* sector.

Section 25 of the *HRA* provides that an individual has a right of access to health information relating to them. If the individual is incapable of giving consent, then the authorised representative may do so. In relation to the *FOI Act* 'any person' has a right of access to a document, other than an exempt document; an exempt document includes documents affecting personal privacy.

9 Section 9: References and resources

- Phil Grano and Robert Salek, *The Right to Die, Advance Directives and Living Wills*

- Phil Grano and Julian Gardner, *Standards of Proof in End of Life Decision-Making*, 2007
- Phil Grano, *The Person Responsible, the Enduring Guardian and the Agent*, 2nd edition.
- Nina Leo *Advance Directives: the Legal Issues*, paper prepared for the Office of the Public Advocate 2004
- Richard Polkinghorn, *Medical and dental treatment (including medical treatment at end of life)*, draft guideline 2009
- John Chesterman *What Force Should We Give To Advance Health Statements*
- NSW Capacity Toolkit
- Medical Practitioners Board of Victoria Medico Legal Guidelines 2006 (<http://www.medicalboardvic.org.au>)
- AMA Code of Ethics
- *A Question of Right Treatment: The Family Court and Special Medical Procedures for Children 1998* (www.familycourt.gov.au)
- Family Court, Practice Direction No. 9 of 2004 - Victorian and Queensland Registries: Medical Procedure Applications (www.familycourt.gov.au)
- “Disability Residential Services Palliative Care guide: End-of-life care for residents of disability residential services” (DHS)

A hard copy of the The Law Handbook is available in the legal unit. It can be accessed on line: www.lawhandbook.org.au