CONSENTING TO TREATMENT

DEVELOPING AN A.C.T. LEGISLATIVE FRAMEWORK
FOR GIVING CONSENT TO PROVIDING,
WITHHOLDING OR WITHDRAWING
MEDICAL TREATMENT TO AN INCOMPETENT ADULT

DISCUSSION PAPER

JUNE 2007

SUBMISSIONS ARE SOUGHT ON ISSUES RAISED IN THIS DISCUSSION PAPER

The paper is divided into three parts.

The first part is a general introduction. The second part addresses decision making around the provision of treatment to an adult patient who is not capable of entering into decisions about their own treatment.

The third part addresses decision making around the withholding or withdrawal of treatment to an adult patient who is not capable of entering into decisions about their own treatment.

The ACT Government will consider submissions before deciding on how to provide a legislative framework for decision-making about the provision of treatment and the withholding or withdrawal of treatment to an incompetent adult patient.

The paper demonstrates that many of the underlying principles and issues that relate to decision making for the provision of treatment are similar to those relating to decision-making for the withholding or withdrawal of treatment.

Because the two issues are addressed together in this discussion paper it should not be concluded that the government is committed to providing a legislative framework for both. It is possible, for example, that a decision could be made to implement a scheme that addresses only decision making for the provision of treatment and not to legislate for the withholding or withdrawal of treatment.

Persons may make submissions on all, or some, of the issues raised in the paper.

Submissions close at 5pm Friday 24 August 2007, and should be sent to:

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DISCUSSION PAPER QUESTIONS – EXECUTIVE SUMMARY

The following questions arise out of the issues discussed in the paper. The issues themselves are discussed in detail throughout the paper.

STATUTORY HEALTH ATTORNEYS

1. Should family members or relatives of a person who has no decision-making ability be allowed to consent to medical treatment for the person?

2. Should family members or relatives of a person who has no decision-making capability be allowed to consent to both non-urgent and urgent medical treatment for the person?

3. If the ACT were to implement a statutory health attorney system should it adopt a hierarchy of responsible persons?

4. Who should be such attorneys?

- *What order of priority should be given to them?*
- *What role would the Public Advocate play in such a system?*

5. Should statutory health attorneys be appointed by the guardianship tribunal?

6. If so, should the request for such appointment be made through the Public Advocate?

7. If not, what residual role should the Public Advocate or the tribunal play in such a system?

8. What matters should be specified to allow a statutory health attorney to reach an informed position on giving consent?

9. How should a statutory health attorney be selected for appointment within the framework of the order of priority for statutory health attorneys?

10. Should a person appointed as a statutory health attorney meet the same or similar requirements for appointment as a guardian?

11. Should a person appointed as a statutory health attorney be required to comply with the same or similar decision-making principles under the guardianship legislation?

WITHDRAWING OR WITHHOLDING TREATMENT

12. How might compliance to these requirements and principles be best ensured?

13. Is the common law adequate to cater for consent to the withholding or withdrawal of medical treatment to an incompetent patient?

14. Should a legislative framework be developed to cater for consent to the withholding or withdrawal of medical treatment to an incompetent patient?

15. Should ACT law allow for medical practitioners treating an incompetent patient to act alone in deciding to withhold or withdraw medical treatment that was considered futile according to best medical practice?

16. Should ACT law require medical practitioners treating an incompetent patient to consult with and gain consent from an authorised person before withholding or withdrawing medical treatment that was considered futile according to best medical practice?

17. Who should be included as persons authorised to make consent to the withholding or withdrawal of medical treatment to incompetent patients?

18. Should there be an order of priority in selecting the authorised person?

19. On what basis might a person lower in order be selected over persons who are higher in the order?

20. What should be the role of the Public Advocate?

21. Should a statutory health attorney be appointed by the guardianship tribunal to give consent to the withholding or withdrawal of medical treatment?

22. What matters are to be considered in the best interests of an incompetent person where a decision is to be made for the withholding or withdrawing of medical treatment to the person?

23. Should consent for the withholding or withdrawing medical treatment to a person be based on a medical opinion, made in good faith and in accordance with good medical practice that commencing, or continuing with, treatment to a person is futile?

24. Depending on the model established, what information should a doctor provide to the tribunal, Public Advocate or statutory health attorney to seek an informed consent to the withholding or withdrawal of medical treatment?

25. Should legislation provide for the protection of a doctor from civil and criminal liability if the doctor –

- *acts in good faith and in accordance with good medical practice in making a decision that commencing, or continuing with, treatment to a person is futile, and*

- *withholds or withdraws the treatment on the basis of the consent from the relevant statutory health attorney, provided the doctor believes the consent is an informed consent, or on the basis of the consent from the Public Advocate, acting as guardian with power to give such consent?*

PART 1: INTRODUCTION

This discussion paper is divided into three parts. The first part is a general introduction. The second part examines issues relating to substituted consent for providing treatment to an incompetent adult, where the person has not made a direction or enduring power of attorney[1]. The third part examines issues relating to withholding or withdrawing medical treatment to an incompetent person, where the person has not made a direction or enduring power of attorney.

In this paper the person to whom the proposed treatment relates is sometimes referred to as the 'patient'.

Providing treatment

1.1 The provision of medical treatment to a person requires the person's consent[2], except where the treatment is of an urgent nature. There are times when a patient is incapable of giving consent as, for example, if a person is in a coma, or is intellectually disabled. Patients who believe their condition may eventually lead to their inability to make decisions for themselves can, under existing ACT legislation, appoint another person under an enduring power of attorney to act on their behalf, including for giving consent to treatment.

1.2 In other jurisdictions, when no such attorney has been appointed, a medical practitioner can seek consent to provide treatment from the next of kin.

1.3 In the ACT, there is no enabling legislation to allow a family member or a relative of a person to consent to a person's medical treatment. It is often disturbing to a family member, to be told that they cannot give consent to medical treatment for a loved one, for example an adult child, spouse or aged parent.

1.4 Where there is no previously appointed attorney, the ACT Public Advocate can give consent to treatment of an incompetent person as emergency guardian.

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[1] These circumstances are dealt with under medical treatment and power of attorney legislation in the ACT.

[2] Queensland Law Reform Commission, *Assisted and Substituted Decisions*, Report No. 49, Volume 1 (June, 1996), p.311: "In the absence of consent, even the slightest degree of bodily contact may give rise to a civil claim for damages for assault or to a criminal assault charge.

This general rule applies to the performance of health care procedures on a patient who has not given his or her consent. In the absence of a valid consent, treatment which involves any touching of the patient's body will constitute an assault even if the treatment is properly carried out. The requirement of consent is intended to ensure protection for the patient against unauthorised interference with his or her right to bodily integrity and for the health care provider against possible legal action."

Withholding or withdrawal of treatment

1.5 Medical treatment to a person can be withheld or withdrawn in the ACT if the person has made a direction for that purpose or, if not capable of making that decision has previously authorised another person under an enduring power of attorney to consent to such a decision. In relation to a person who has not made a direction or an enduring power of attorney, ACT law does not provide for anyone to consent to withhold or withdraw treatment. It has been the practice of doctors to consult family members of a patient, or the Public Advocate, acting as guardian, before making a decision about the withholding or withdrawal of medical treatment. This paper examines whether this practice should be put within a legislative framework.

Human rights considerations

1.6 This discussion paper examines the need or otherwise to implement a legislative framework for substitute decision making for patients who are not capable of making decisions about their medical treatment.

1.7 If the ACT were to implement such a legislative framework the ACT would need to have regard to the *Human Rights Act 2004* (ACT). The rights which are most relevant to the withholding or withdrawing of medical treatment are the right to life (s9); the right of self-determination in relation to medical treatment (s10(2)); and the right to privacy (s12). Also of relevance are the right to equality and non-discrimination (s8) and the prohibition against cruel, inhuman and degrading treatment (s10(1)).

The positive obligation to protect life

1.8 Human rights jurisprudence has generally accorded pre-eminence to the right to life (s9) as a foundational human right.[3] The right to life requires the State not only to refrain from the intentional and unlawful taking of life, but also to take appropriate steps to safeguard the lives of those within its jurisdiction.[4] These principles extend to the public health sphere and impose positive obligations on the State to ensure that hospitals adopt appropriate measures for the protection of patients' lives.[5]

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[3] *McCann and Others v United Kingdom*, judgment of 27 September 1995, Series A no 324

[4] *LCB v United Kingdom*, judgment of 9 June 1998, 1998-III

[5] *Calvelli and Ciglio v. Italy* [GC], no. 32967/96, ECHR 2002-I; Burke v UK

The right to personal autonomy

1.9 Section 10(2) protects a person's right to autonomy and personal, mental and bodily integrity in the context of medical treatment.[6] This right of self-determination includes the right to determine what medical treatment will be accepted and the extent to which it will be accepted. The right to refuse applies whether or not the treatment will harm or benefit the person, or would save his or her life.[7]

1.10 The right to privacy in section 12 extends to cover the physical and psychological integrity of a person.[8] Choices about a person's own body in the context of medical treatment and how a person manages his/her death also fall in principle within its scope.[9]

Reasonable limits

1.11 Under s28, human rights may only be subject to reasonable limits which are 'demonstrably justified in a free and democratic society'. Therefore any limitation of rights must pursue a legitimate objective and there must be a reasonable relationship of proportionality between the means employed and the objective sought to be realised. Proportionality requires that the limitation:

- be necessary and rationally connected to the objective;
- be the least restrictive in order to accomplish the objective; and
- not have a disproportionately severe effect on the person to whom it applies.

Human rights compatible models

1.12 A human rights consistent framework for the withholding or withdrawal of medical treatment must necessarily operate from the presumption in favour of life-sustaining treatment except where such a presumption would conflict with the (competent) patient's right to refuse treatment.[10]

1.13 Statutory or common law models which include the following features have generally been found to achieve an appropriate balance between

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[6] The UN Human Rights Committee has stated that medical treatment without consent may meet the general definition of cruel, inhuman and degrading treatment when it causes suffering or degradation: see Concluding Comments on Japan (1998) UN doc. CCPR/C/79/Add. 102, para.31.

[7] *Mallette v Shulman* [1991] 2 Med LR 162; *Re MB* [1997] 8 Med LR 21

[8] *X and Y v. the Netherlands*, judgment of 26 March 1985, Series A no. 91.

[9] *Pretty v. United Kingdom*, no. 2346/02, ECHR 2002-III; Burke v UK

[10] There is no corollary human right for a (competent or incompetent) patient to demand the provision of treatment which the doctor considers is not clinically justified: see eg Burke v UK

the State's obligation to protect life and the individual's right to self-determination in matters of medical treatment:

- A competent adult has the right to refuse medical treatment;[11]
- An incompetent adult has the right to refuse medical treatment where s/he has made an advance directive which is both valid and relevant to the treatment in question;[12] and
- A substitute decision-maker may refuse medical treatment for an incompetent adult (who has not made a valid advance directive) only by reference to the patient's best interests.
- Substitute decision makers - need for clear guidance and safeguards

1.14 In order to be consistent with the right to life, any decision to refuse treatment for a person who lacks capacity must be in the person's 'best interests'. For example, human rights jurisprudence has confirmed that the withdrawal of artificial nutrition and hydration from a patient in a permanent vegetative state does not constitute a breach of the right to life because the positive obligation to prolong life only arises where such treatment is in the patient's best interests.[13]

Summary of relevant cases

1.15 A summary of relevant case law can be found at **Appendix 2**.

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[11] See eg, *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871; *Re T (Adult: Refusal of Treatment* [1992] 2 FLR 458; *Ciarlariello v. Schacter*, [1993] 2 S.C.R. 119; *In re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290; *Re MB (Medical Treatment)* [1997] 2 FLR 426; and *Re B (Consent to Treatment: Capacity)* [2002] EWHC 429 (Fam), [2002] 1 FLR 1090.

[12] *Fleming v. Reid* (1991), 4 O.R. (3d) 74 (Ontario Court of Appeal); *HE v A Hospital NHS Trust* [2003] EWHC 1017 (Fam), [2003] 2 FLR 408

[13] *Glass v UK [2004] ECHR 2003; R(Burke)v GMC&others[2005]EWCA 1003.*

PART 2: CONSENT TO PROVIDE MEDICAL TREATMENT TO AN INCOMPETENT ADULT, AND THE ROLE OF FAMILY MEMBERS AND RELATIVES

THE CURRENT POSITION IN THE ACT

Lawful consent to medical treatment

2.1 An adult can give consent for his or her medical treatment. An adult person (principal) can also appoint another person under an enduring power of attorney authorising that person (attorney) to consent to medical treatment being provided to the principal when the principal's decision-making capacity has become impaired. Patients who believe that their condition may eventually lead to them becoming incapacitated sometimes take this course of action.

2.2 Under common law, medical practitioners can lawfully provide urgent treatment without the patient's consent in some circumstances. This happens frequently. A patient may have suffered a heart attack or been involved in an accident and is not able to give consent to treatment. In such emergencies medical personnel apply urgently needed treatment.

2.3 Medical treatment to an incompetent adult, other than urgent treatment, would require consent on the patient's behalf. A guardian appointed for an incompetent adult could give such consent.

2.4 Currently, guardians for persons with impaired decision-making ability are appointed by the Guardianship and Management of Property Tribunal (the guardianship tribunal) under the *Guardianship and Management of* Property *Act 1991* (the guardianship legislation).

2.5 The guardianship tribunal may appoint a guardian if it is satisfied that someone has impaired decision-making ability in relation to a matter pertaining to the person's health or welfare and there is, or is likely to be, a need for a decision in relation to that matter. The tribunal will also need to be satisfied that, if a guardian is not appointed, the person's needs could not be met, or the person's interests will be significantly adversely affected.

2.6 One of the powers that may be given to a guardian by the tribunal is the power to give, a consent required for a medical procedure or other treatment (other than a prescribed medical procedure).[14]

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[14] The guardianship legislation, Dictionary explaines that "prescribed medical procedure" means –

(a) an abortion; or

(b) reproductive sterilisation; or

(c) a hysterectomy; or

(d) a medical procedure concerned with contraception; or

The decision-making ability of a person is defined as being impaired if it "is impaired because of a physical, mental, psychological or intellectual condition or state, whether or not the condition or state is a diagnosable illness".[15]

Appointment of guardian

2.7 The guardianship legislation provides for matters to be considered by the guardianship tribunal when appointing a guardian. A person can be appointed as a guardian with his or her written consent.[16] The Public Advocate, the public trustee or a trustee company can be appointed as a guardian or manager. Otherwise any adult not under guardianship themselves can be appointed provided they have informed the guardianship tribunal on oath about whether they

(a) have been convicted or found guilty of an offence involving violence, fraud or dishonesty; or

(b) have been, either in the ACT or elsewhere, refused appointment as a guardian or manager, or removed from office as a guardian or manager; or

(c) are bankrupt or have executed a personal insolvency agreement

2.8 The guardianship tribunal must also be satisfied that the person will follow the decision-making principles and is otherwise suitable for appointment.[17]

(e) removal of non-regenerative tissue for transplantation to the body of another living person; or

(f) treatment for mental illness, electroconvulsive therapy or psychiatric surgery; or

(g) any other medical or surgical procedure prescribed for this definition.

[15] Section 6, guardianship legislation.

[16] Section 10(1), guardianship legislation.

[17] Section 10(3), Guardianship legislation, provides that the guardianship tribunal must take into account the following matters when appointing a guardian *(The references to 'manager' have been omitted in reproducing these matters.)*:

(a) the views and wishes of the person for whom a guardian is to be appointed; and

(b) the desirability of preserving existing family relationships; and

(c) whether the 2 people are compatible; and

(d) whether the proposed guardian lives in the ACT; and

(e) whether the proposed guardian will be available and accessible to the other person; and

2.9 Section 5 of the guardianship legislation which provides for decision-making principles is set out in **Appendix 2** to this Discussion Paper.

2.10 In non-urgent situations, the tribunal is required to hold an inquiry before making orders and this can take some time. Regularly, the provision of medical treatment, while not necessarily being urgent in any emergency sense, cannot be delayed for the length of time it would take for the tribunal to set up an inquiry to appoint a guardian. In such circumstances the tribunal can appoint an emergency guardian without setting up an inquiry.

Role of Public Advocate under section 67 of the guardianship legislation

2.11 Reference to the terms "emergency guardian", "non-urgent" and "urgent" needs some clarification.

2.12 If a patient who is incapable of making decisions needs immediate life saving or health treatment medical practitioners can and do provide that treatment without needing to seek consent from any other party. (If non-urgent treatment for the patient is envisaged at some time into the future then the guardianship tribunal may be requested to appoint a guardian following an inquiry).

2.13 If treatment is required not as an immediate response to a health crisis, but nonetheless in a shortened time frame of perhaps a few days, then the tribunal may appoint an emergency guardian, without holding an inquiry.

2.14 The guardianship tribunal may appoint the Public Advocate as a guardian without inquiry if the tribunal is satisfied that there are special circumstances of urgency that make it proper to do so. In special circumstances of urgency, the tribunal may also appoint the Public Advocate or the Public Trustee as a manager of the property of a person with impaired decision-making ability.

2.15 Medical staff (at the level of Registrar or above) complete the application for emergency guardianship and the Public Advocate, if she agrees with the assessment of impaired capacity, applies to the guardianship tribunal to be appointed as substitute decision maker. This process is used on a regular basis to obtain consent to non-urgent medical treatment, procedures and operations.

(f) the nature of the functions to be exercised under the order and whether the proposed guardian is competent to exercise them; and

(g) whether the interests and duties of the proposed guardian are likely to conflict with the other person's interests to the detriment of the person's interests.

(note: The interests and duties of a domestic partner or a relative must not be taken to be likely to conflict with the interests of the person only because of the fact of being the domestic partner or relative (cf. section 10(5), guardianship legislation).)

2.16 Emergency guardianship only operates for 10 days. If consent continues to be required after that period, and there is no authorised person available to give consent, the tribunal order is renewed on the application of the Public Advocate.

2.17 On average, over 10 new medical consent emergency guardian requests are made in the ACT each month. It is not unusual for them to be extended two to three times. About 30% of orders last for 10 days and about 5% of orders are renewed repeatedly for up to three to four months.

2.18 Currently, there is no provision to appoint a family member of a patient as an emergency guardian.

LAW IN OTHER JURISDICTIONS

2.19 Most other jurisdictions in Australia have provided a legislative framework that allows a range of persons to consent to the treatment of patients who are not capable of consenting to treatment for themselves.

2.20 In some jurisdictions, the scope for selecting substitute decision makers extends beyond close family members and relatives, to include friends and carers of a patient. They are referred to variously as a "person responsible", or a "statutory health attorney". This paper uses both terms and in this paper the reference to medical treatment includes dental treatment.

2.21 The selection of the person whose consent is to be obtained in a given situation, provided they are available and considered suitable, is decided according to their ranking in a hierarchy as follows (This information is available in a tabular form for easy reference in **Appendix 3**):

2.22 *New South Wales[18] ("person responsible")*

a) the person's guardian, if the instrument of appointment includes the function of giving consent to medical or dental treatment;

b) the spouse of the person if the relationship between the person and the spouse is close and continuing, and the spouse is not a person under guardianship;

c) a person who has the care of the person;

d) a close friend or relative of the person.

2.23 *Queensland[19] ("statutory health attorney")*

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[18] *Guardianship Act 1987* (NSW), section 33A.

[19] *Powers of Attorney Act 1998* (Qld), section 63.

a) the spouse of an adult if the relationship between the adult and the spouse is close and continuing;

b) a person who has the care of the adult and not a paid carer;

c) a close friend or relation of the adult.

2.24 *Victoria*[20] *("persons responsible"*)

a) a person appointed by the patient under the *Medical Treatment Act 1988* (Vic) to give consent to medical treatment;

b) a person appointed by the Victorian Civil and Administrative Tribunal;

c) a person appointed under a guardianship order;

d) an enduring guardian[21];

e) a person appointed by the patient to make decisions in relation to medical research purposes;

f) the patient's spouse or domestic partner;

g) primary carer of the patient;

h) nearest relative.

2.25 *Tasmania*[22] *("persons responsible")*

a) for a patient under 18 – spouse, and if there is no spouse, the person's

I. parent;

b) for a patient over 18 –

I. guardian;

II. spouse;

III. carer;

IV. close friend or relative.

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[20] *Guardianship and Administration Act 1986* (Vic), section 37.

[21] An enduring guardian is a person appointed by the appointer to make decisions for personal care, including medical decisions, for the appointer during the time the appointer has no capacity. The ACT does not provide for enduring guardians, but an enduring power of attorney may give an attorney similar functions as for enduring guardians.

[22] *Guardianship and Administration Act 1995* (Tas), section 4.

2.26 *South Australia*[23] *("appropriate authority")*

a) a guardian, whose power to consent to medical treatment is not excluded;

b) a relative;

c) the Guardianship Board.

2.27 *Western Australia*[24] *("person responsible")*

A Bill before the WA Parliament proposes to amend the *Guardianship and Administration Act 1990* (WA) to provide for the following order:

a) spouse or de facto partner,

b) nearest relative who maintains a close personal relationship with the patient,

c) primary carer (not remunerated), and

d) any other person who maintains close personal relationship with the patient.

A POSSIBLE ACT LEGISLATIVE MODEL

Is there a role for the family or other persons in the ACT?

2.28 It is doctors who form a view about the treatment to be given to a person, and the person consenting to it will generally rely on the professional accountability of doctors.

2.29 While laws in other jurisdictions provide for family members to be able to consent to medical treatment to a patient, in the ACT, the Public Advocate must be contacted for cases where the hospitals want consent to treatment for patients who do not have capacity. Doctors and the Public Advocate now consult family members and relatives of the patient. This may support the view that it is family members and relatives who have a clear interest in the wellbeing and health of a patient, and their right to consent to treatment should therefore be recognised.

2.30 It is not uncommon for relatives and friends of incompetent patients who have made no prior arrangements for decision making to be deeply upset when they learn that they are not able, under ACT law, to consent to the treatment of their loved ones.

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[23] *Guardianship and Administration Act 1993* (SA), section 59.

[24] Acts Amendment (Consent to Medical Treatment) Bill 2006 (WA).

2.31 Family members and relatives typically visit family patients regularly and may often be in contact with the treating medical practitioners. It would be convenient for medical practitioners not only to explain matters to them but also to seek the required consent.

2.32 Should the law in the ACT be brought into line with law in other jurisdictions to provide for the right of immediate family members and other close associates to consent to "non-urgent" and "urgent" medical treatment to an incompetent patient?

2.33 Should a patient's family members, relatives, carers or close friends who could be trusted and capable of making decisions in the best interests of the patient, be permitted to do so under ACT legislation?

2.34 On the other hand, is it more appropriate to rely on the statutory accountability of the Public Advocate to ensure that decisions on treatment are made in a reasonable and proper manner on the basis that a family member may not have similar skills or accountability? Might personnel from the Public Advocate's office be less emotionally involved, and/or be better able to weigh up the advice and provide a more objective view, especially in times of crises?

DISCUSSION QUESTIONS:

1. *Should family members or relatives of a person who has no decision-making ability be allowed to consent to medical treatment for the person?*

2. *Should family members or relatives of a person who has no decision-making capability be allowed to consent to both non-urgent and urgent medical treatment for the person?*

Who could be appointed as statutory health attorneys?

2.35 If a legislative framework for statutory health attorneys were established, should a hierarchy of responsible persons be adopted, who should be included, and in what order? There may be occasions where no substitute decision maker could be found, either in the short term or in the long term. Or, at times, there may be disagreement between family members, or confusion about the nature or of treatment being recommended. Although in those cases where there is a degree of confusion, rather than disagreement, then in the first instance the resources of the treating facility, such as a social worker, could be the used first to help responsible persons process the information necessary to reach a decision about consent. If family members are in dispute it may be necessary to retain a power to revert to the guardianship legislation. Where a person who has interest in a patient does not agree with a decision made by a statutory health attorney, consideration should be given to providing the person a right to apply to the guardianship tribunal within a prescribed time limit for a review of the decision. Such a measure would ensure oversight by the tribunal of the appropriateness of the decision.

2.36 Where no substitute decision maker can be identified, for whatever reason, it may then be appropriate for the Public Advocate to act as the responsible person of last resort.

DISCUSSION QUESTION:

3. If the ACT were to implement a statutory health attorney system should it adopt a hierarchy of responsible persons?

- *Who should be such attorneys?*
- *What order of priority should be given to them?*
- *What role would the Public Advocate play in such a system?*

Appointment of statutory health attorneys

2.37 In other jurisdictions statutory health attorneys (or persons responsible) are not appointed by a tribunal or court. Generally, the decision making about who should be the nominated authorised person is carried out by the medical bureaucracy after giving due consideration as to the selection criteria, as to the persons who might be available to act in the role of the substitute decision maker, and after undertaking the procedural safeguards required to appoint the authorised person.

2.38 The argument for keeping the decision-making solely within the medical setting is threefold. Firstly, the final responsibility and accountability for getting the decision right would rest with the medical authority and therefore care will be taken in making sure that the most appropriate authorised person was selected. Secondly, if the decision-making is to also involve the Public Advocate and, or the tribunal, then one, or two, additional layers of bureaucratic, time consuming, decision-making is added. Thirdly, involvement of the tribunal and the Public Advocate in all such appointments is likely to over extend the current resources of both of these agencies.

2.39 Alternatively in the ACT statutory health attorneys could be appointed by the guardianship tribunal. This might arguably ensure the interests of a patient are best protected, not only in relation to appointing statutory health attorneys but also in relation to the relevant medical decision to give treatment, including the type of treatment. The tribunal is required to comply with section 30 of the *Human Rights Act 2004*. Under that section, in working out the meaning of a Territory law, an interpretation that is consistent with human rights is preferred. In other words, tribunal involvement might better ensure decisions are made consistently with human rights principles. The practicalities of this approach need to be thought through.

2.40 A reasonably straightforward procedure could be for the social worker or ward staff to complete a form following the selection of the statutory health attorney. This would be faxed directly to the tribunal, or perhaps to the Public Advocate who would then send it to the tribunal to officially

make the appointment. If sent directly to the tribunal, the tribunal would need to have confidence in the way the nomination had been decided on up to that point in time. If sent through the Public Advocate the tribunal would be informed by the one central agency and the process would ensure that the Public Advocate is able to monitor the system of consenting to medical treatment. Currently, hospitals contact the Public Advocate regularly on a number of matters, including medical consent matters, and the Public Advocate contacts the guardianship tribunal in relation to a number of applications she makes to it.

DISCUSSION QUESTIONS:

4. Should statutory health attorneys be appointed by the guardianship tribunal?

5. If so, should the request for such appointment be made through the Public Advocate?

6. If not, what residual role should the Public Advocate or the tribunal play in such a system?

Informed consent

2.41 "A real consent is one which is based on a broad understanding of the proposed treatment and which is not induced by fraud or by misrepresentation as to the nature of the procedure."[25] A statutory health attorney would need to give informed consent to treatment.

2.42 In New South Wales[26], a request to a person responsible for a patient specifies:

- the ground on which consent is required;
- the particular condition of the patient;
- the alternative courses of treatment available;
- the general nature and effect of such courses of treatment;
- the nature and degree of the significant risks (if any) associated with each of the courses of treatment; and
- the reasons why any particular treatment should be carried out.

2.43 The person responsible must have regard to the views (if any) of the patient, the matters set out in the request, and the objects of the part of the NSW guardianship legislation that deals with medical and dental treatment.

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[25] Supra 2 (Queensland Law Reform Commission Report on "Assisted and Substituted Decisions") , p.311.

[26] NSW Guardianship Act, section 40.

2.44 Some patients may have previously expressed firm views about possible future treatment regimes or may hold religious beliefs about forms of treatment. Some may have written down directions about advanced health care. The ACT currently does not have any legislative scheme for the express recognition of advance health directives. The recognition of valid advance directives to refuse treatment, subject to necessary safeguards, is a logical and appropriate continuation of respect for the individual's autonomy in matters of medical treatment. It is proposed to address this issue separately from this discussion paper.

2.45 The process of acquiring informed consent could include a requirement to seek out and have regard to, what the views of the patient may have been, including views expressed by the patient in any form, whether in writing (such as an informal note, an advance directive made in accordance with the law of another jurisdiction or a directive written under a mistaken belief that it is acceptable in the ACT) or verbally.

DISCUSSION QUESTION:

7. What matters should be specified to allow a statutory health attorney to reach a informed position on giving consent?

Selection of a statutory health attorney

2.46 If a system of statutory health attorneys is implemented it is possible at a given time that the person who is the first or second in the order of priority would not be available to give consent to medical treatment. It could also be likely that someone who is higher in the order of priority would be available, but would not be suited for appointment, perhaps because they may be too frail, or emotionally overwhelmed.

2.47 In Queensland, to be a statutory health attorney, a person needs to be readily available and culturally appropriate to exercise power for a health matter.[27] In order to allow sound decisions to be made, what is 'readily available' and what is 'culturally appropriate' are not defined. It would appear that in Queensland the order of priority with regard to statutory health attorneys would, then, operate only where there are two or more eligible persons readily available and who are culturally appropriate.

2.48 If a hierarchical system was established, should medical authorities be required to take reasonable steps to identify and locate a person starting from the top of the hierarchy?

2.49 A doctor or hospital may find a person who is readily available. However, it would be not always possible for them to engage in an inquiry as to whether a person is culturally appropriate to give consent. The term "cultural appropriateness" suggests having an understanding

[27] Section 63, *Powers of Attorney Ac*t (Qld).

of the wishes of another in their cultural system of beliefs, preferences, practices and expectations.

DISCUSSION QUESTION:

8. *How should a statutory health attorney be selected for appointment within the framework of the order of priority for statutory health attorneys?*

Additional considerations in appointing a statutory health attorney

2.50 As discussed previously, the guardianship tribunal must have regard to matters set out in the legislation before appointing a guardian (refer to the section on Appointment of guardian).

2.51 Should a statutory health attorney be appointed only when similar conditions to those set out in the legislation are satisfied and should statutory health attorneys need to make a decision in accordance with the decision-making principles under the guardianship legislation, set out in the Schedule 1 appended to this paper. If statutory health attorneys are to comply with them, how might compliance be monitored without making the process too complex?

DISCUSSION QUESTIONS:

9. *Should a person appointed as a statutory health attorney meet the same similar requirements for appointment as a guardian?*

10. *Should a person appointed as a statutory health attorney be required to comply with the same or similar decision-making principles under the guardianship legislation?*

11. *How might compliance to these requirements and principles be best ensured?*

PART 3: CONSENT TO THE WITHHOLDING OR WITHDRAWAL OF MEDICAL TREATMENT TO AN INCOMPETENT ADULT, AND THE ROLE OF FAMILY MEMBERS AND RELATIVES

THE CURRENT POSITION

3.1 Consent to the withholding or withdrawal of medical treatment to an incompetent adult is an issue of interest to the ACT community. Medical treatment for a patient can be withheld or withdrawn in accordance with a direction given by the patient under the Medical Treatment (Health Directions) Act 2006. A person may also authorise an attorney under an enduring power of attorney to consent to the withholding or withdrawal of medical treatment generally, or of a specific medical treatment, to the person. The Powers of Attorney Act 2006 provides for enduring powers of attorney28. No other ACT legislation deals with the issue of withholding or withdrawal of medical treatment.

3.2 It is important to note that such decisions do not constitute acts of euthanasia. Euthanasia relates to the deliberate administration of some form of treatment or the carrying out of some action that would directly bring about the imminent death of the patient, as opposed to the non-administration of treatment that, using a best medical practice test, was considered futile.29

3.3 There is also a distinction between the provision of nutrition and hydration by normal means in the context of palliative care, and the use

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[28] Until 30 May 2007, a direction to withhold or withdraw medical treatment was able to be made under the *Medical Treatment Act 1994*, which is repealed. The provisions of the 1994 Act dealing with directions have been re-written into the Medical Treatment (Health Directions) Act. The repealed Act provided also for enduring powers of attorney for withholding or withdrawing medical treatment, which have not been re-drafted. This is because the Powers of Attorney 2006 now provides for such powers of attorney.

[29] *Australian Capital Territory (Self-Government) Act 1988* (Cth), Section 23(1A) provides that the Legislative Assembly has no power to make laws permitting or having the effect of permitting (whether subject to conditions or not) the form of intentional killing of another called euthanasia (which includes mercy killing) or the assisting of a person to terminate his or her life. Section 23(1B) provides:
"The Assembly does have power to make laws with respect to:

(a) the withdrawal or withholding of medical or surgical measures for prolonging the life of a patient but not so as to permit the intentional killing of the patient; and

(b) medical treatment in the provision of palliative care to a dying patient, but not so as to permit the intentional killing of the patient; and

(c) the appointment of an agent by a patient who is authorised to make decisions about the withdrawal or withholding of treatment; and

(d) the repealing of legal sanctions against attempted suicide."

of artificial means of nutrition and hydration, which has been considered a form of medical treatment.30

3.4 Whether giving or continuing medical treatment to a patient is futile is a medical decision. In the case of a patient who is incompetent, the practice in the ACT has been for doctors:

- to consult with family members and relatives of the patient, and
- where no such person is available to agree to the decision, or where there is a conflict of views, to consult with the Public Advocate, acting as emergency guardian.

3.5 Concurrence of relevant people in this consultation is often thought of as a means for those consulted to provide consent to the medical decision to withhold or withdraw medical treatment. The general belief is that this consultation practice, and the giving of consent by a family member to withdraw medical treatment to a patient, is permitted, or even required, in the common law. To the extent that this issue has been tested by the courts, however, the weight of judicial opinion suggests that at law the decision to make a decision about the withholding or withdrawal of medical treatment is a medical one, not one to which another adult can consent as such.

3.6 However, reliance on the common law to make such a decision, or to give consent to such a decision is fraught, particularly because the position under the common law in the ACT cannot be said to be free from ambiguity.

3.7 There are overseas decisions that support a decision about withholding or withdrawal of medical treatment based on medical opinion.[31]

Some common law considerations

3.8 The following segment is a summary of relevant common law findings.

Who can decide to withhold or withdraw life-sustaining treatment for an incompetent adult at common law?

The Doctor as Decision Maker.

3.9 Medical treatment that an incompetent adult needs can be given without consent, based on the doctrine of necessity: In re F (Mental Patient: Sterilisation) [1990] 2 AC 1.

3.10 In comparable jurisdictions, such as the United Kingdom, the common law has conferred a degree of protection to health care professionals

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[30] Gardner; Burke v UK;

[31] *Airdale N.H.S Trust v Bland* [1993] AC 789; *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235.

through the doctrine of necessity. The courts in the UK have identified four circumstances where the non-treatment of incompetent patients by doctors is legally acceptable:

- Inevitable death in the short term, whatever therapy is provided; [32]
- Firm diagnosis of persistent vegetative state;[33]
- Severe brain damage, although the person may not be dying or in severe pain;[34]
- Great pain and suffering, although not necessarily associated with a terminal condition, with the prospect of a demonstrably awful life.[35]

3.11 However, the common law has never given third parties the power to give consent on behalf of an incompetent adult.

3.12 The *Mental Capacity Act 2005 (*UK) codifies the common law, providing protection to health care professionals who reasonably believe that their actions will be in the best interests of the patient.

3.13 The decision must be based on an assessment of what is in the 'best interests of the patient'[36].

- The primary factor considered under the 'best interests' test is responsible medical opinion, that is, whether from a medical perspective it is appropriate to continue treatment. Doctors have no duty to administer futile treatment[37].
- Other factors taken into account to different degrees under the best interests test include the views and values of the adult (to the extent that they can be ascertained) and the views of the family. Sometimes these other factors have been assigned weight as criteria independent

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[32] *Re C* [1989] 2 All ER 782, CA.

[33] *Airedale NHS Trust v Bland* [1993] 1 All ER 821, HL.

[34] Re J [1990] All ER 930, CA.

[35] *Re B [1981] 1 WLR 1421, CA*

[36] *Airedale NHS Trust v Bland* [1993] AC 789; *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235; *Re G* [1997] 2 NZLR 201).

[37] *Barber v Superior Court*, 195 Cal. Rptr. 484 (Cal. App. 1983); *Airedale NHS Trust v Bland,* [1993] 1 All E.R. 821 (H.L.); and *Auckland Area Health Board v A.G*.,[1993] 1 N.Z.L.R.235.

from responsible medical opinion.[38] At other times they have been taken into account as part of making an informed medical decision[39].

The Court as decision maker

3.14 A superior court, such as the Supreme Court, has inherent jurisdiction to make decisions for incompetent adults under its parens patriae jurisdiction[40].

3.15 The Court may also provide declaratory relief by ruling whether a proposed decision to withhold or withdraw life-sustaining treatment is lawful (as opposed to making the decision).[41]

3.16 To date, the rule that court approval is needed for medical decisions relating to non-therapeutic procedures with potentially 'grave consequences'[42] has not been applied to the withholding or withdrawal of life-sustaining treatment from an incompetent adult.

3.17 Where the legality of withdrawing or withholding treatment is in doubt, the doctor should seek Court approval as a matter of good practice.[43] In other words, the Court need only be involved where there is a disagreement between those involved and those close to the patient, about the patient's best interests.

The role of third parties

3.18 At common law, third parties do not have the power to make decisions to withhold or withdraw life-sustaining treatment on behalf of an incompetent adult.

3.19 Their views may however be taken into consideration under the best interests test, that is, acting in the best interests is likely to require consultation with a range of people including anyone interested in the patient's welfare (see above).

The common law in Australia

3.20 There is scant Australian precedent in these types of cases. Recent decisions, however, suggest that the Australian common law position is

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[38] For example, *Re G* [1997] 2 NZLR 201.

[39] *Airedale NHS Trust v Bland* [1993] AC 789; *Auckland Area Health Board v Attorney – General* [1993] 1 NZLR 235.

[40] *In re F (Mental Patient: Sterilisation)* [1990] 2 AC 1

[41] *R (Burke) v GMC & others* [2005] EWCA 1003; *Airedale NHS Trust v Bland* [1993] AC 789 and *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235.

[42] (eg, sterilisation: *Re S (Sterilisation)* [2000] 2 FLR 389).

[43] *R (Burke) v GMC & others* [2005] EWCA 1003.

likely to be broadly consistent with the position in other common law jurisdictions, as outlined above.

3.21 A superior court has inherent jurisdiction to make decisions for incompetent adults under its *parens patriae* jurisdiction[44]. The exercise of the *parens patriae* jurisdiction should not be for the benefit of others, whether the hospital or the family.[45] Intervention, based on the *parens patriae* jurisdiction should be cautious.[46] A court will be reluctant or cautious to intervene unless it is necessary:[47]

3.22 A decision to withhold or withdraw treatment is a medical matter at first instance.[48] However, technically, a court is not bound to give effect to the medical opinion, even where it is unanimous.[49] In reality, a court will rarely act against unanimous medical opinion that treatment is futile, burdensome or demeaning:

> 'The [Supreme] court … has jurisdiction to prevent the withdrawal of … treatment, support and sustenance where the withdrawal may put in jeopardy the life, good health or welfare of such unconscious individual. What constitutes appropriate medical treatment in a given case is a medical matter in the first instance. However, where there is doubt or serious dispute in this regard the court has the power to act to protect the life and welfare of the unconscious person': Northridge, per O'Keefe J at [24].
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> '[T]he treatment of the patient, where, as here, the Court is satisfied that decision as to the appropriate treatment is being made in the welfare and interest of the patient, is principally a matter for the expertise of professional medical practitioners … Apart from extending the patient's life for some relatively brief period, the current treatment is futile. I believe that it is also burdensome and will be intrusive to a degree. I am not satisfied that this Court's jurisdiction has been enlivened by the evidence before me from the family members' Messiha per Howie J at [25].
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> 'An approach based upon that analysis, also, I think, would have required the granting of the present application [to withdraw treatment], simply because that approach, properly applied to the given facts of this case, would not have left available to the Court any proper residual

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[44] *Department of Health and Community Services (NT) v JWG* (1992) 175 CLR 218 **('Marion's Case')**; *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549.

[45] *Northridge*, citing *Re Eve* (1987) 31 DLR (4th) 1.

[46] *Northridge*, citing *Marion's Case*.

[47] *Messiha v South East Health* [2004] NSWSC 1061.

[48] *Northridge; Messiha; Krommydas v Sydney West Area Health Service* [2006] NSWSC 901.

[49] *Messiha*.

discretions which might have enabled the Court itself to intervene so as to ensure some phased withdrawal of the current regime of ventilation rather than its immediate termination' Krommydas, per Sully J at 9).

3.23 Arguably, a court will consider that it has limited discretion to intervene unless there is evidence that the withholding or withdrawal of treatment is contrary to medical practice.

3.24 It cannot be said with certainty that court decisions elsewhere establish the common law position in the ACT, particularly in the absence of any ACT decision.

3.25 With respect to what has been ACT practice, questions remain as to:

- Whether doctors can lawfully withdraw medical treatment from a patient in the absence of a direction made by the patient under the Medical Treatment Act; and

- whether the Public Advocate, acting as guardian, can consent to the withdrawal of medical treatment to an incompetent patient except in terms of a direction given by the patient under the Medical Treatment Act, and where there is no direction, whether the Public Advocate must seek the approval of the Supreme Court.

3.26 As ACT legislation does not expressly address the matter, ambiguity as to the legality of decision-making will persist until one day it becomes a seriously justiciable issue. That noted, arguably no obvious problem has surfaced to date in the operation of the current system of doctors making a decision about the withholding or withdrawal of medical treatment, in consultation with the relevant persons referred to above.

3.27 This should not lead to unquestioning acceptance that the common law as it is presumed to be, and the decision-making based on professional medical opinion, would be enough to resolve the issue. Moreover, in the context of increasing awareness about rights and responsibilities, the community could feel that the rights of an incompetent patient, and of the patients' family members, were being undermined covertly.

3.28 In order to ensure that a decision about withholding or withdrawal of medical treatment in relation to an incompetent patient is taken with due regard to the patient's rights, and that the community's need to have a proper guidance on this issue is addressed, it may be preferable that the statute law clarifies the position. However it is also conceivable that no statutory regime will be sufficient to cover all eventualities and that codifying the situation may make an already sensitive and difficult time of life overly bureaucratic and prone to litigation.

3.29 It is at least timely to consider whether statutory frameworks established in other jurisdictions might be applicable to the ACT to provide for substituted decision-making by family members and relatives for the withholding or withdrawal of medical treatment to an incompetent patient.

DISCUSSION QUESTIONS:

12. Is the common law adequate to cater for consent to the withholding or withdrawal of medical treatment to an incompetent patient?

Or

13. *Should a legislative framework be developed to cater for consent to the withholding or withdrawal of medical treatment to an incompetent patient?*

LAW IN OTHER JURISDICTIONS

3.30 A number of jurisdictions have now provided for substituted decision-making by family members and relatives for the withholding or withdrawal of medical treatment to an incompetent patient.

3.31 Queensland

A statutory health attorney may make a decision to withhold or withdraw a life-sustaining measure for an adult with impaired capacity.[50] Under the *Guardianship and Administration Act 2000* (Qld)[51], a health matter of an adult with impaired capacity, including the withholding or withdrawal of medical treatment may only be dealt with in the following order of hierarchy:

a) in accordance with an advance health directive made by the adult;

b) by a guardian;

c) by an attorney appointed under an enduring power of attorney for a health matter;

d) if none of the above applies, by a statutory health attorney.

The Adult Guardian of Queensland (who is equivalent to the ACT Public Advocate) may also be appointed as a guardian.

Consent to the withholding or withdrawal of medical treatment cannot operate unless the adult's health provider reasonably considers the commencement or continuation of the life-sustaining measure for the adult would be inconsistent with good medical practice.[52]

The Guardianship and Administration Act allows urgent or minor health care to an adult to be able to be provided without consent. Although an urgent health

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[50] Powers of Attorney Act (Qld) – sections 62 and 63, and Schedule 2, Part 2, items 4 and 5 (definitions of health matter and health care). The Queensland legislation uses the expression "withholding or withdrawal of a life-sustaining measure", not "withholding or withdrawing of medical treatment".

[51] Guardianship and Administration Act (Qld) – section 66.

[52] Ibid, section 66A.

care does not include withholding or withdrawal of a life-sustaining measure for an adult,[53] section 63A of this Act expressly empowers a health provider to withhold or withdraw such a measure for an adult with impaired capacity for the health matter, without consent, if the "commencement and continuation of the measure… would be inconsistent with good medical practice", and the decision to withhold or withdraw the measure must be "consistent with good medical practice".

Good medical practice is defined as:

"good medical practice for the medical profession in Australia having regard to –

a) the recognised medical standards, practices and procedures of the medical profession in Australia; and

b) the recognised ethical standards of the medical profession in Australia".[54]

It has been the practice in the ACT that a medical decision to withhold or withdraw treatment to an incompetent patient is taken through a collaborative process involving family members and relatives, or the Public Advocate, acting as emergency guardian. It would appear the Queensland legislation extends this process by allowing for relevant people to "consent" to the decision.

3.32 Victoria

The *Medical Treatment Act 1988* (Vic) provides for an agent or guardian, on behalf of a patient, to refuse medical treatment generally or medical treatment of a particular kind.[55] As an agent is appointed under an enduring power of attorney, that appointment is not relevant for the purpose of the discussion paper.

A guardian is appointed under the *Guardianship and Administration Act 1986* (Vic), for the purpose of the Medical Treatment Act, by an order providing for decisions about medical treatment.[56] Where there is no person suitable to be appointed as a guardian, the Victorian Civil and Administrative Tribunal may appoint theVictorian Public Advocate as the guardian.[57]

Before a guardian may refuse medical treatment to the represented person, a registered medical practitioner and another person should each be satisfied that the guardian has been informed about the nature of the patient's current condition to an extent that would be reasonably sufficient to enable the patient, if

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[53] Ibid, sections 63 and 64.

[54] Ibid – Schedule 2, Part 2, item 5B.

[55] *Medical Treatment Act* (Vic), s.5B.

[56] Ibid, s.5A, and *Guardianship and Administration Act* (Vic), s.3.

[57] *Guardianship and Administration Act* (Vic), s.23(4).

he or she were competent, to make a decision about whether or not to refuse medical treatment, and that the guardian understands the information.[58] The guardian may only refuse medical treatment "if:

a) the 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".[59]

The guardian should sign a refusal of treatment certificate.

3.33 Western Australia

The most recent legislative measure to deal with consent to the withholding or withdrawal of medical treatment is found in Western Australia.

The Acts Amendment (Consent to Medical Treatment) Bill 2006 in amending the *Guardianship and Administration Act 1990* (WA) provides for the power of a "person responsible" to refuse to consent to the commencement or continuation of any treatment of the patient.[60]

A person responsible could make such a decision only where there is no enduring guardian or a tribunal-appointed guardian, authorised to make the decision.[61] The Bill defines "treatment decision" to mean a decision to consent or refuse to consent to the commencement or continuation of any treatment to a person. A "person responsible" for a patient is any of the following:

a) the patient's spouse or de facto partner, if over 18 and living with the patient;

b) the patient's nearest relative over 18 who maintains a close personal relationship with the patient; and

c) the person who is over 18 and provides primary care and support (including emotional support) to the patient but not remunerated for such care and support.[62]

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[58] *Medical Treatment Act* (Vic), s.5B(1).

[59] Ibid, s.5B(3).

[60] Proposed section 110ZD provides that a person responsible for a patient is the first in the order of the listed persons who is of full legal capacity, is reasonably available, and is willing to make a treatment decision in respect of the treatment. Also, proposed amendment to section 3 defines a "treatment decision" to be "a decision to consent or refuse to consent to the commencement or continuation of any treatment of the patient".

[61] Proposed section 110ZJ.

[62] Proposed section 110ZD(3).

A patient's nearest relative is the first in the order of priority from:

a) the spouse or de facto partner;

b) a child;

c) a parent; and

d) a sibling.[63]

A close personal relationship is defined to mean that the person has frequent contact of a personal (not a business or professional) nature with the patient, and takes genuine interest in the patient's welfare.[64]

3.34 South Australia

The *Consent to Medical Treatment and Palliative Care Act 1995* (SA) provides that there is no duty on a medical practitioner to use, or to continue to use, life sustaining measures in treating a patient, if using those measures would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state".[65] This would happen where there is no express direction by the patient or the patient's representative to the contrary.[66] This process appears to be comparable to the process prevailing in the ACT where, in practice, there is a consultative process involving family members of a patient, or the Public Advocate, acting as emergency guardian, before a decision about withholding or withdrawal of medical treatment is made.

3.35 Tasmania

The Guardianship and Administration Act 1995 (Tas) provides that a full guardian appointed by the Guardianship and Administration Board has power to refuse or withdraw consent to medical treatment to the represented person.

A POSSIBLE ACT LEGISLATIVE MODEL

3.36 If an ACT legislative framework is to be considered, the following threshold questions need to be addressed.

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[63] Proposed section 110ZD(4).

[64] Proposed section 110ZD(5).

[65] Section 17(3), *Consent to Medical Treatment and Palliative Care Act* (SA).

[66] A patient's representative is a person a person empowered by medical power of attorney or some

other lawful authority to make decisions about medical treatment to a person who is incapable of making decisions.

DISCUSSION QUESTIONS:

14. Should ACT law allow for medical practitioners treating an incompetent patient to act alone in deciding to withhold or withdraw medical treatment that was considered futile according to best medical practice?

OR

15. Should ACT law require medical practitioners treating an incompetent patient to consult with and gain consent from an authorised person before withholding or withdrawing medical treatment that was considered futile according to best medical practice?

3.37 If it is agreed that doctors should consult with other persons, the further question arises as to who should be consulted.

3.38 Should the same categories of persons as those canvassed in Part 2 for the consenting to the provision of treatment apply to decision making about the withholding or withdrawal of treatment, or might it be argued that a decision about the withholding or withdrawal of treatment warrants consideration of a different range of persons?

3.39 It might be argued that consent to withholding or withdrawing medical treatment to an incompetent patient is too onerous an obligation to be left to a family member, relative, or close associate, since they would not have sufficient detachment from emotions that might cloud their consideration of whether the decision is in the best interests of the patient. It could also be argued that they would be vulnerable to pressure to give, or not to give, consent.

3.40 In light of these arguments, it could further be argued that the Public Advocate is better able to protect the rights of an incompetent patient and should be authorised to give consent to a decision about withholding or withdrawal of medical treatment.

3.41 On the other hand it is likely that family members and other close associates of a patient will have been closely involved in many other decisions in the patient's life and so should not be shut out at such a significant time. They may also have the best awareness of any particular sensitivities for the patient.

3.42 It should be noted that a family member, relative or close associate can currently be authorised under an enduring power of attorney to consent to a decision about withholding or withdrawal of medical treatment.

3.43 Bypassing family members of a patient to seek the consent of the Public Advocate, may raise strong objection from family members.

3.44 As noted in Part 2, at times persons towards the top of a hierarchical list of eligible responsible persons might be unable to participate in decision making for a variety of reasons, such as availability, or they themselves may not be well enough to participate.

3.45 As described in Part 2, might the Public Advocate be called on when no other authorised person could be identified or when there was a disagreement about the decision among those persons eligible to be authorised persons?

DISCUSSION QUESTIONS:

16. Who should be included as persons authorised to make consent to the withholding or withdrawal of medical treatment to incompetent patients

17. Should there be an order of priority in selecting the authorised person?

18. On what basis might a person lower in the order be selected over persons who are higher in the order?

19. What should the role of the Public Advocate be?

Should a statutory health attorney be authorised by the guardianship tribunal?

3.46 Do the same considerations apply for tribunal intervention, or otherwise, in appointing statutory health attorneys for consenting to a decision about withholding or withdrawal of medical treatment? Would the tribunal be better placed to consider the principle of "best interests" of a patient objectively than an individual who may be related to the patient?

3.47 On the other hand, it could be argued that

- it is those who have kinship with the patient or a close relationship with the patient who will better know the wishes and feelings of the patient;
- hence, they may be better suited to decide what is in the best interests of the patient; and
- what is in the best interests of the patient should not be a judicial or quasi-judicial set standard, but should be a standard set by a common person with kinship or close ties to the patient.

3.48 As discussed previously, under Queensland legislation, and under the Western Australia Bill, statutory health attorneys appointed to consider decisions about the withholding or withdrawal of treatment are not appointed via a guardianship tribunal, but in Tasmania only a Board-appointed guardian is given this power.

DISCUSSION QUESTION:

20. Should a statutory health attorney be appointed by the guardianship tribunal to give consent to the withholding or withdrawal of medical treatment?

Best interests

3.49 The House of Lords in *Airdale N.H.S. Trust v Bland* expressed the view that the fundamental criterion for making a decision to withdraw medical treatment to an incompetent patient is in the best interests of the patient having regard to the established medical practice.[67] It is evident from the decision that the question of whether medical treatment is futile is a medical decision. The Court also said that doctors could discontinue life-prolonging treatment where it was no longer in the best interests of the patient to continue with it.[68] Even in circumstances where a decision to discontinue treatment could be made, the court distinguished between (a) where the best interests of a patient would need to be weighed before making a decision, and (b) where no benefit would be served by continuing the treatment and no weighing process is needed.[69] In both classes of case, a medical decision is to be made by weighing up the best interests of the patient, even where the outcome of that consideration would be that the interests of the patient would not be served by continuing treatment. It would be appropriate to regard such an outcome as being in the best interests of the patient, having regard to the human worth, dignity, pain and suffering, of the patient.

3.50 ACT guardianship legislation sets out what are a person's interests and provides for decision-making principles (see **Appendix 2** to this paper). These provisions were made when there was no legislative intent to provide for the withholding or withdrawal of medical treatment. They need to be examined further to see if they adequately provide for the best interests of a person in terms of a decision about the withholding or withdrawal of treatment.

3.51 The *Mental Capacity Act 2005* (UK) provides that a person determining what is in another person's best interests in relation to life-sustaining treatment, should not be motivated by a desire to bring about the death of the other person.[70] The UK Act places the following obligations on a person making a determination:

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[67] [1993] AC 789, per Lord Goff of Chiveley at p.867.

[68] Ibid, at p.868.

[69] Ibid, at p.868-9.

[70] Mental Capacity Act (UK), s.4(5).

- The person "must consider, so far as is reasonably ascertainable –
  - the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
  - the beliefs and values that would be likely to influence his decision if he had capacity, and
  - the other factors that he would be likely to consider if he were able to do so."
- The person must also take into account, if it is practicable and appropriate to consult them, the views of anyone named by the other person to be consulted, anyone engaged in caring for that person or interested in that person's welfare, any donee of a lasting power of attorney (i.e. equivalent of an enduring power of attorney) of that person, and any deputy appointed for that person by the court.[71]

3.52 In the ACT, the *Powers of Attorney Act 2006* provides for conditions an attorney authorised under an enduring power of attorney should comply with before asking for withholding or withdrawing medical treatment to the principal (i.e. the person to whom the attorney acts). The attorney must believe, on reasonable grounds, that the principal would ask for withholding or withdrawing medical treatment if the principal could make a rational judgement, and were to give serious consideration to the principal's own health and wellbeing. Where a statutory health attorney is to be authorised to consent to the withholding or withdrawal of medical treatment for a person, it would be appropriate to provide for similar considerations.

3.53 Similar provisions can be found in the Ontario *Health Care Consent Act, 1996*.[72]

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[71] Ibid, s.4(6) and (7).

[72] Section 21 provides that a person who gives or refuses consent to a treatment to an incapable person should act according to wish of the latter if the former knows that wish, and if it is impossible to comply with the wish, act in the incapable person's best interests. The best interests include the following considerations:

- the values and beliefs that the person knows the incapable person held;
- any wishes expressed by the incapable person with respect to the treatment; and
- the following factors:
  - Whether the treatment is likely to,
    - i. improve the incapable person's condition or well-being,
    - ii. prevent the incapable person's condition or well-being from deteriorating, or

DISCUSSION QUESTION:

21. What matters are to be considered in the best interests of an incompetent person where a decision is to be made for the withholding or withdrawing of medical treatment to the person?

Role of doctors in relation to the withholding or withdrawal of medical treatment

3.54 As discussed before, the question of whether to commence or continue with medical treatment to a person is futile is a medical decision made in accordance with what is good medical practice. Where doctors seek consent of a statutory health attorney, consideration should be given to the kind of information they should provide to obtain an informed consent to the withholding or withdrawal of medical treatment.

3.55 In the ACT, the *Powers of Attorney Act 2006* requires an attorney, before asking to withhold treatment, to consult a doctor about the nature of the principal's illness, any alternative forms of treatment available to the principal, and the consequences of the principal remaining untreated. A doctor providing such information to a statutory health attorney would be acting in accordance with accountability and diligence, while helping the attorney to provide an informed consent.

3.56 In Queensland, the *Guardianship and Administration Act 2000* (Qld) provides that a consent to the withholding or withdrawal of a life-sustaining measure for an adult cannot operate unless the adult's health provider reasonably considers that commencement or the continuation of the measure would be inconsistent with good medical practice.

3.57 It is evident from the decision in Bland that good medical practice is the basis for the validity of a decision to withhold treatment.

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iii. reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate.

- Whether the incapable person's condition or well-being is likely to improve, remain the same or deteriorate without the treatment.
- Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.
- Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed

3.58 Where a doctor forms an opinion based on good medical practice that it is futile to commence, or continue with, treatment to a person, accountability demands that the doctor explain the reason for that opinion to anyone whose consent the doctor requires.

3.59 If withholding or withdrawal of medical treatment is to be recognised in statute law, the need to expressly provide for the protection of doctors who act in good faith and in accordance with good medical practice should also be considered, without prejudice to the existing common law protection.

DISCUSSION QUESTIONS:

25. *Should consent for the withholding or withdrawing medical treatment to a person be based on a medical opinion, made in good faith and in accordance with good medical practice, that commencing, or continuing with, treatment to a person is futile?*

26. *Depending on the model established, what information should a doctor provide to the tribunal, Public Advocate or statutory health attorney to seek an informed consent to the withholding or withdrawal of medical treatment?*

27. *Should legislation provide for the protection of a doctor from civil and criminal liability if the doctor –*

    - *acts in good faith and in accordance with good medical practice in making a decision that commencing, or continuing with, treatment to a person is futile, and*

    - *withholds or withdraws the treatment on the basis of the consent from the relevant statutory health attorney, provided the doctor believes the consent is an informed consent, or on the basis of the consent from the Public Advocate, acting as guardian with power to give such consent?*

APPENDIX 1

Summary of case law decisions which involved withholding or withdrawal of medical treatment to incompetent patients

see para 1.15 of this Discussion Paper

English cases:
(in chronological order)

- ***In re F. (Mental Patient: Sterilisation)***
  [1990] 2 AC 1

F was a mentally handicapped woman, who resided in a mental hospital as an in-patient. She had the mental age of a child. She formed a sexual relationship with a male patient. The hospital staff considered that she would be unable to cope with the effects of pregnancy and giving birth. It was considered that all forms of contraception were unsuitable, and that it would be in her best interests to be sterilised. F's mother sought a declaration for such an operation.

The House of Lords affirming the decisions of the lower court and the Court of Appeal held that it was open to a court under its inherent jurisdiction to make the declaration sought on the grounds that the proposed operation was in the best interests of the patient. The purpose of the operation was to prevent the risk of an incapacitated woman, who was unable to consent to the operation, becoming pregnant rather than the treatment of diseased organs. It also said that it was not satisfactory to leave this grave decision with all its social implications in the hands of those having care of the patient and that they must obtain the approval of the court.

- ***Airedale N.H.S Trust v Bland***
  [1993] AC 789

As a result of injuries sustained in a disaster when he was at the Hillsborough football ground, Anthony Bland had been in the condition known as persistent vegetative state when his case first came before the courts in 1992. His condition arose from the destruction, through prolonged deprivation of oxygen, of the cerebral cortex, which had resolved into a watery mass. He could not communicate in any way. On the other hand the brain stem, which controls the reflexive functions of the body, in particular heartbeat, breathing and digestion, continued to operate. In order to maintain life, artificial feeding and hydration were given.

The medical opinion was that there was no prospect whatever that he would ever make any recovery from his present condition, but that there was every likelihood that he would maintain his present state of existence for many years to come, provided that the medical care he was receiving continued. The medical professionals in charge of his case formed the view, which was supported by his parents, that no useful purpose was to be served by

continuing that medical care and that it was appropriate to stop the artificial feeding and other measures aimed at prolonging his existence.

The House of Lords decided that the patient had no further interest in being kept alive in a vegetative state and that the principle of sanctity of life, which was not absolute, was not violated by ceasing to give medical treatment and care to him.

- ***R (on the Application of Burke) v The General Medical Council***
  [2005] EWCA Civ. 2003

Mr Burke was 45 years of age. He suffered from a congenital degenerative brain condition known as spino-cerebellar ataxia, which confined him to a wheelchair. This was a progressively degenerative condition that follows a similar course to multiple sclerosis. He suffered very serious physical disabilities but has retained his mental competence and capacity. He had uncoordinated movements and his condition also affected his speech, but his mental ability was not impaired

By reason of his condition there would come a time when the claimant would be entirely dependent on others for his care and indeed for his very survival. In particular he would lose the ability to swallow and would require ANH (i.e. artificial nutrition and hydration) by tube to survive.

The evidence was as follows: Until his final days the claimant, although by then being kept alive by ANH, would retain both his capacity to make decisions for himself and an ability to communicate his wishes, albeit probably via a computerised device. During his final days he would lose the ability to communicate, although not at first an awareness and appreciation of his surroundings and predicament. He would then lapse into a semi-comatose condition before dying.

Burke wanted to be fed and provided with appropriate hydration until he would die of natural causes. He did not want ANH to be withdrawn. He did not want a decision to be taken by doctors that his life was no longer worth living.

The Court of Appeal (Civil Division) in England held that while a competent patient had a right to refuse to treatment, it did not follow that a patient had a right to be provided with any form of treatment that he might consider to be in his own best interests. The doctor's duty to provide treatment is a positive duty at common law to care for a patient. It further held that the common law recognised two exceptions to this duty, i.e. (1) where a competent patient refuses treatment, and (2) where the patient is incompetent and it is not in the patient's best interests to keep him alive artificially.

The Court also said that once the claimant (Mr Burke) ceased to be competent, however, the circumstances might arise where his previously expressed wish might conflict with the doctor's professional opinion that ANH would not provide overall clinical benefit, and that in such circumstances, the

doctor was not obliged to administer a treatment that the doctor considered adverse to the patient's needs.

Australian cases:
(in chronological order)

- ***Secretary, Department of Health and Community Services v J.W.B and S.M.B. [Marion's case]***
  [1992] 175 CLR 218

Marion was the pseudonym of a teenager who was 14 years old at the time this case came up before the Court. She suffered from mental retardation, severe deafness and epilepsy, had an ataxic gait and "behavioural problems". She could not care for herself. Her parents, who were married in 1976 and who, with their children, were residents of the Northern Territory, applied to the Family Court of Australia for an order authorising performance of a hysterectomy and an ovariectomy on Marion; alternatively, a declaration that it was lawful for them to consent to the performance of those procedures.

A hysterectomy was proposed for the purpose of preventing pregnancy and menstruation with its psychological and behavioural consequences; an ovariectomy was proposed in order to stabilise hormonal fluxes with the aim of helping to eliminate consequential stress and behavioural responses. The term "sterilisation" was used in the judgment to refer to both proposed procedures.

The High Court held that Applicants, as joint guardians of the child, could not lawfully authorise the carrying out of a sterilisation procedure upon the child without a Court order and that the Family Court had jurisdiction to authorise such a procedure. However, it agreed that the Court could neither enlarge the powers of the guardian to authorise, nor approve the consent of the guardians to, the proposed procedure. Nevertheless, the Court said that in authorising such a procedure, the Family Court, may, if necessary, permit the Applicants to give any requisite consent.

Further, the High Court held that except where sterilisation was an incidental result of a surgery performed to cure a disease or correct some malfunction, the decision to sterilise an intellectually disabled minor fell outside the ordinary scope of parental powers and therefore, outside the scope of the powers, rights and duties of a guardian. Deane J in his minority view said that parents could authorise sterilisation if it was obviously in the interests of an intellectually disabled child, after due inquiry and adequate consideration of what truly represented the child's welfare, and that where sterilisation was not so obviously necessary, the court's authorisation was necessary.

- ***Northridge v Central Sydney Area Health Service***
  (2000) 50 NSWLR 549

Over the objections of a patient's family, medical practitioners at the Royal Prince Alfred Hospital in Sydney stopped antibiotics and feeding for an unconscious patient who had been admitted to the hospital. Doctors gave direction not to resuscitate the patient if his bodily functions ceased. The family applied to the Court for orders that treatment and feeding be recommenced.

The Supreme Court of NSW traced the origin of the *parens patriae* jurisdiction of the Supreme Court to one of the prerogatives of the Crown to the right to take care of the person and property of those who by virtue of disability were unable to do so for themselves. "The parens patriae jurisdiction of the Supreme Court extends to the protection of the life and bodily integrity of persons who are unable to do so for themselves because of various exigencies, one of which is unconsciousness."

The Court commented on the absence of a standard for the making of a diagnosis of chronic vegetative state, and a standard or guidelines in relation to the withdrawal of medical treatment and artificial feeding from patients who were diagnosed as being in such a vegetative state.

The Court ordered that the patient should be provided with necessary and appropriate medical treatment directed towards the preserving of his life and the promoting of his good health and welfare, and that no not for resuscitation order should be made without prior leave of the Court.

- ***Gardner; re BWV***
  [2003] VSC 173

On 28 February 2003 the Victorian Civil and Administrative Tribunal appointed the Public Advocate to be a limited guardian of BWV, a woman aged 68 years who suffers from dementia. The appointment as a limited guardian of BWV included powers and duties to make decisions concerning her medical treatment.

BWV suffered from a progressive and fatal form of dementia, probably Pick's Disease. She had not appeared conscious, or to have had any cortical activity, for approximately three years. She appeared to have no cognitive capacity at all and had no non-reflexive bodily functions, other than those which are reflexive. Further, she appeared to have no conscious perception of input from any of her sensory pathways. BWV received fluid and nutrition, via a percutaneous endoscopic gastrostomy ("PEG"), which process kept her alive.

BWV required full nursing care: she was doubly incontinent; she received regular pressure care; she was moved into a shower by a hoist; and she received medications through the PEG.

Although the brain stem of BWV continued to function normally, the medical evidence was that the damage to the cortex was irreparable. There was no

prospect of any recovery, or improvement of any kind in BWV's condition. The evidence of the three medical witnesses who examined BWV was that the provision of nutrition and hydration, via the PEG, was futile.

The Public Advocate sought declarations from the Court that:

> (a) provision of nutrition and hydration via the PEG constituted "medical treatment" within the meaning of the term in the *Medical Treatment Act 1988* (Vic); and (b) refusal of further nutrition and hydration via PEG constituted refusal of "medical treatment", rather than refusal of "palliative care", within the meaning of that Act.

The significance of the distinction between "medical treatment" and "palliative care", in the context of the *Medical Treatment Act* revolved around the provisions of that Act, which effectively allows a guardian, on behalf of a patient, to refuse medical treatment, but not to refuse palliative care.

If the declarations sought were made, the Public Advocate, on behalf of BWV, intended to refuse further nutrition and hydration via the PEG (subject to satisfying certain other conditions required by the Act). If this occurred BWV would die within one to four weeks of the withdrawal of such nutrition and hydration.

The Victorian Supreme Court decided that the provision of nutrition and hydration via PEG constituted 'medical treatment' and its refusal constituted refusal of medical treatment, rather than refusal of 'palliative care'.

- ***Isaac Messiha (by his tutor Magdy Messiha) v South East Health*** *[2004] NSWSC 1061 (11 November 2004)*

On 17 October 2004 Mr Messiha, a patient of 75 years of age, was admitted to the Intensive Care Unit of St George Hospital. He had suffered an asystolic cardiac arrest: that is his heart had completely stopped beating depriving his body, including his brain, of the supply of oxygen. As a result, since his admission, the patient had been unconscious and apparently in a deep coma.

The Director of the Unit determined that the current treatment regime of the patient should cease and that he should be removed from the Unit and placed under palliative care. She accepted that withdrawing treatment in the Unit would have the effect of reducing his life expectancy. Members of the patient's family applied to the Court in order to restrain the Director and other medical staff at the hospital from altering the patient's treatment. The family believed that, contrary to medical opinion, there were some slight signs of improvement in the patient's condition and that, if the current treatment regime continued, thus prolonging his life by even a short period of time, the patient's condition might improve.

The application to the Court was based upon its *parens patriae* jurisdiction. The Court said that, "What constitutes appropriate medical treatment in a given case is a medical matter in the first instance. However, where there is

doubt or serious dispute in this regard the court has the power to act to protect the life and welfare of the unconscious person."

It also said that the Court was not bound to give effect to the medical opinion, even where, as here, it was unanimous, but that it seemed that it would be an unusual case where the Court would act against what was unanimously held by medical experts as an appropriate treatment regime for the patient in order to preserve the life of a terminally ill patient in a deep coma where there was no real prospect of recovery to any significant degree.

The Court found that apart from extending the patient's life for some relatively brief period, the treatment to the patient was futile. It also believed that it was also burdensome and would be intrusive to a degree. The Court was not satisfied that the withdrawal of the patient's treatment was not in the patient's best interest and welfare.

APPENDIX 2

Relevant Provisions of the Guardianship Legislation

see paras 2.8, 3.50 of this Discussion Paper

Section 4

What are a person's *interests*?

A person's ***interests*** include the following:

(a) protection of the person from physical or mental harm;

(b) prevention of the physical or mental deterioration of the person;

(c) the ability of the person to—

(i) look after himself or herself; and

(ii) live in the general community; and

(iii) take part in community activities; and

(iv) maintain the person's preferred lifestyle (other than any part of the person's preferred lifestyle that is harmful to the person);

(d) promotion of the person's financial security;

(e) prevention of the wasting of the person's financial resources or the person becoming destitute.

Section 5

Principles to be followed by decision-makers

(1) This section applies to the exercise by a person (the ***decision-maker***) of a function under this Act in relation to a person with impaired decision-making ability (the ***protected person***).

(2) The ***decision-making principles*** to be followed by the decision-maker are the following:

(a) the protected person's wishes, as far as they can be worked out, must be given effect to, unless making the decision in accordance with the wishes is likely to significantly adversely affect the protected person's interests;

(b) if giving effect to the protected person's wishes is likely to significantly adversely affect the person's interests—the decision-maker must give effect to the protected person's wishes as far as possible without significantly adversely affecting the protected person's interests;

(c) if the protected person's wishes cannot be given effect to at all—the interests of the protected person must be promoted;

(d) the protected person's life (including the person's lifestyle) must be interfered with to the smallest extent necessary;

(e) the protected person must be encouraged to look after himself or herself as far as possible;

(f) the protected person must be encouraged to live in the general community, and take part in community activities, as far as possible.

(3) Before making a decision, the decision-maker must consult with the primary carer of the protected person, unless doing so would, in the

decision-maker's opinion, adversely affect the protected person's interests.

(4) Subsection (3) does not limit the consultation that the decision-maker may carry out.

APPENDIX 3

Statutory health attorneys in other Australian jurisdictions

see para 2.20 of this Discussion Paper

		QLD	SA	TAS	VIC	WA
Guardian	✓		✓	✓		
Spouse – incl de facto partner	✓ if close and continuing	✓ if close and continuing	✓	✓	✓	✓
Relative NSW	✓	✓	✓	✓	✓	✓
Carer - unpaid	✓	✓		✓	✓	✓
Close friend	✓	✓		✓		✓
Enduring guardian					✓	
Guardianship Bd			✓			
Person appointed by other means					✓ (incl under Medical treatment Act or by VCAT)	