Submission
No 36

INQUIRY INTO SUBSTITUTE DECISION-MAKING FOR PEOPLE LACKING CAPACITY

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By email

Dear Mr Clark

Submission to the Inquiry into substitute decision-making for people lacking capacity – problems with end-of-life decisionmaking

I would like to bring to the Committee's attention several problems with substitute decision-making that have occurred in the area of end-of-life decisionmaking. The problems relate specifically to the operation of Part 5 of the Guardianship Act 1987 ('the Act'). In this submission I will outline the legal principles of end-of-life decisions and provide examples of recent cases which highlight the need for change.

Background principles of end-of-life decisions

1. *Death is now a managed process*

It is a fact of life that in modern times we no longer die in the same way that we used to. Whereas in the past we were more likely to die at home or work, in modern times we die in hospitals or nursing homes. This is likely to have been caused by improvements in paramedicine, emergency care and intensive care. Ageing of the population and improvements in the care of people with chronic conditions have added to this phenomenon. By living longer we experience greater levels of chronic disease and disability leading us into institutional settings where we spend our last days. The process of dying has therefore been radically altered.

One the issues that has arisen in relation to the increasing number of medical interventions is the problem of choosing when they should be made available to patients and when they should be withdrawn. Essentially, the success of modern medicine has created the problem of how we manage dying.

Both common law and modern medical ethics emphasise the benefits of maximising the patient's autonomy in the process of dying. It is well acknowledge that the best systems for managing the dying process are ones that include the patients, their families and the care staff so that they work together to maximise the patient's interests.

It is imperative that the legal system provide basic structures for this to occur. Moreover the legal system should also provide clear principles and dispute resolution mechanisms so that disputes can be dealt with efficiently and effectively and in ways that protect the patient from abuse. If we assessed the NSW guardianship legislation against these criteria it abjectly fails to provide clarity or certainty and may well be increasing the amount of abuse of patients. It is quite frankly in a very poor state. Other states have gone through quite considerable reforms in guardianship law in the last decade and have made marked improvements to the regulation of dying.

I should stress from the outset that I am not talking about any form of schema which would condone euthanasia. The issues I discussed are concerned with fundamental rights and processes that have been recognised in all common law countries and, indeed in all Australian jurisdictions, apart from NSW. These are issues upon which there is broad consensus across the spectrum of ethical and religious approaches to dying. This is law which will, at some point or another, affect every single person living in NSW. It is time for the NSW Parliament to act and the Inquiry is extremely timely.

2. *Competent adult patients have the right to refuse treatment*

The fundamental operating principle in this area is that a competent patient has the right to refuse treatment, even if they die as a result. In *Re T (An Adult) (Consent to Medical Treatment)* [1992] 2 Fam 458, Lord Donaldson MR at 460 said:

> This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent...

In the same case Butler-Sloss LJ stated: 'A decision to refuse medical treatment by a patient capable of making the decision does not have to be sensible, rational or well considered': at 474. Straughton LJ agreed: 'An adult whose mental capacity is unimpaired has the right to decide for herself whether she will or will not receive medical or surgical treatment, even in circumstances where she is likely or even certain to die in the absence of treatment': at 478.

In Australia, the Queensland Guardianship and Administration Tribunal has upheld the decision of a competent man to refuse treatment. In *Re PVM* [2000] QGAAT 1, a 39-year-old aboriginal man with traumatic brain and spinal cord damage was not found to be incompetent to refuse ventilation support. His decision to refuse treatment was respected and he was allowed to die. More recently in *Brightwater Care Group Ltd v Rossiter* [2009] WASC 229, the Supreme Court of Western Australian upheld the decision of a quadriplegic man to refuse artificial feeding and hydration.

Of course, the patient must be competent to make a decision. In *Re Bridges* [2001] Qd R 574, a mentally ill patient was found to be incompetent to refuse dialysis, after she has ceased taking her anti-psychotic medication. The court authorised treatment for both dialysis and medication until such times as the medication took effect and the patient had regained competence, after which she could then make a decision regarding her treatment. The Supreme Court of the Act found similarly in *Australian Capital Territory v JT* [2009] ACTSC 105, where a mentally ill patient refused feeding.

3. *Competent patients can make an advance directive to refuse treatment*

One way a patient can deal with incompetence is to plan ahead and give direction about what he or she would like for future care. 'Advance directives' are decisions made by patients about what medical treatments they would like in the future, if at some point, they cannot make decisions for themselves. When thought of in these broad terms, advance directives can be seen as an existing part of everyday medical practice, particularly surgical procedures, where patients consent to treatments many days, even weeks, before they are sedated for their operation. Most academic and legal discussion of advance directives focuses particularly on those decisions about withholding or withdrawing treatments at the end of life. These directives (sometimes referred to as 'living wills') usually record decisions about refusing life-sustaining treatments, but they can also contain the patient's preferences and desires about a whole range of treatment matters.

There are three questions that need to be answered before an advance directive becomes binding:

A. Was the decision-maker competent when they made the directive?

The test for competence was discussed above. In *NHS Trust v T* [2004] EWHC 1279 (see facts above) the woman ws found incompetent to make an advance directive to refuse blood, because of her delusion that her blood was evil and that any transfused blood would be infected by the evil blood. Contrastingly, in *In re W* [2002] EWHC 90, a prisoner with a severe psychiatric disorder was not found incompetent, when he made an advance directive refusing treatment for a self-inflicted wound. The prisoner wounded himself in the shin and repeatedly inserted objects and rubbed faeces into the wound. He had also shoved two tap fittings up his anus, all to protest his prison conditions. His advance directive refusing all treatment was upheld. Butler–Sloss P found that there was no evidence of a lack of competence on the prisoner's part (in fact the deliberate nature of the injuries suggested he was fully competent).

B. Was the advance directive intended to apply in the circumstances that have arisen?

This question is normally answered by an interpretive analysis of the patient's language in their decision and the meaning of particular words and phrases employed. Courts will ordinarily err on the side of preserving life if remote, general, spontaneous or casual comments were made: *Matter of Jobes,* 529 A 2d 434, 443 (NJ, 1987). Contrastingly, evidence of clear and serious decision-making which consists of written evidence or eye-witness accounts is usually strong enough to support the applicability of an advance directive: *Matter of Peter* 529 A 2d 419 (NJ, 1987).

Circumstances sometimes change and the directive may no longer apply. This happened in *HE v A Hospital NHS Trust* [2003] EWHC 1017, where a 24 year old female Jehovah's Witness had signed an advance directive, but had, 2 years later, promised to convert to Islam after becoming engaged to a Muslim. She had been raised as a Muslim but had become a Jehovah's Witness after her parents separated and her mother joined the faith. An application was brought by her father after the woman became seriously ill following an operation. A blood transfusion was deemed necessary by medical staff but the woman's mother was adamant that the directive be followed. Mumby J found the woman's promise to convert back to Islam as an 'essential and compelling aspect' for finding that the advance directive was no longer intended to apply.

C. Was the decision-maker unduly influenced?

Decisions to refuse treatment must be free from the undue influence of others (see Chapter 14). In *Re T (An Adult) (Consent to Medical Treatment)* its was found that an advance directive had been made by a patient (who was not a Jehovah's witness) to refuse blood, but that the patient had made the decision because of the undue influence of the patient's mother (who was a Jehovah's Witness). The court found that the woman's mother had exerted undue pressure on the woman to make her refuse the treatment prior to her becoming incapacitated. The woman's decision was therefore invalid and treatment could be provided by the doctors according to the patient's best interests. The court stated that when examining undue influence, one must inquire as to both the strength of will of the patient and the relationship of the patient with the persuader.

The right to make a common law advance directive was recognised in NSW in the recent case of *Hunter and New England Area Health Service v A* [2009] NSWSC 761. In that case, McDougall J said at [39]:

> By s 6A of the Guardianship Act, an appointment under Pt 2 (which is the part of the Act under which Mr A appointed Messrs T and L) has effect during such period of time as the appointor is a person in need of a guardian. By s 3(1) a "person in need of a guardian" is "a person who, because of a disability, is totally or partially incapable of managing his or her person". It is not necessary to set out, or to consider, the statutory concept of "disability" (see s 3(2) of the Guardianship Act); nor is it necessary to consider the relationship between the statutory concepts of a person having a disability (s 3(2)) and a person incapable of giving consent (s 33(2)). That is because, if the appointment of Messrs T and L as enduring guardians had effect (which it would if Mr A were a person who had a disability), the mechanism for obtaining consent from Mr T or Mr L has not been invoked (see s 40). I do however note that, for the purposes of Pt 5 (see, for example, s 37, and in particular subs (3)(b)), a person is taken to object to the carrying out of medical treatment if, among other things, that person has previously indicated, in similar circumstances, that he or she did not then want the treatment to be carried out, and has not subsequently indicated to the contrary (s 33(3)(b)). Thus, to some extent and for some purposes, the Guardianship Act may give recognition to advance care directives.

All jurisdictions apart from New South Wales and Tasmania have legislative mechanisms for creating advance directives. All these schemes preserve a patient's right to make advance directive at common law (except for South Australia and Queensland). Details of the schemes are attached to Table 1 at the end of this document.

4. *Competent patients can appoint substitute decisionmakers to make medical treatment decisions and incompetent patients may have substitute decisionmakers appointed for them*

Generally speaking, there are five different types of substitute decision-maker in Australia. They are:

- the Supreme Courts of each State an Territory;
- the guardianship authorities (tribunals or boards) in each jurisdiction;
- the guardians they appoint;
- health attorneys, enduring guardians and medical agents appointed by the patient; and
- relatives and friends under 'person responsible' legislation.

Doctors also have power to provide treatment without consent when such treatment is necessary. Health attorneys are referred to as 'enduring guardians' in NSW. Table 1 at the end of this document provides a summary of comparisons between Australian jurisdictions.

5. *The guiding principles of the* **Guardianship Act** *for substitute decisionmaking require*

Section 4 of the Act states:

> It is the duty of everyone exercising functions under this Act with respect to persons who have disabilities to observe the following principles:
> (a) the welfare and interests of such persons should be given paramount consideration,
> (b) the freedom of decision and freedom of action of such persons should be restricted as little as possible,
> (c) such persons should be encouraged, as far as possible, to live a normal life in the community,
> (d) the views of such persons in relation to the exercise of those functions should be taken into consideration,
> (e) the importance of preserving the family relationships and the cultural and linguistic environments of such persons should be recognised,
> (f) such persons should be encouraged, as far as possible, to be self-reliant in matters relating to their personal, domestic and financial affairs,
> (g) such persons should be protected from neglect, abuse and exploitation,
> (h) the community should be encouraged to apply and promote these principles.

Under s 32, any medical or dental treatment that is carried out on such people is carried out for the purpose of 'promoting and maintaining their health and well-being.' Under s 44(2) the Tribunal must consider the following when giving consent to treatment:

> (a) the views (if any) of:
>
> > (i) the patient,
> > (ii) the person who is proposing that medical or dental treatment be carried out on the patient,
> > (iii) any persons responsible for the patient, and
>
> (b) the matters referred to in section 42 (2) [which are:
>
> > (a) the grounds on which it is alleged that the patient is an incompetent patient,
> > (b) the particular condition of the patient that requires treatment,
> > (c) the alternative courses of treatment that are available in relation to that condition,
> > (d) the general nature and effect of each of those courses of treatment,
> > (e) the nature and degree of the significant risks (if any) associated with each of those courses of treatment, and
> > (f) the reasons for which it is proposed that any particular course of treatment should be carried out] ; and
> > (c) the objects of this Part [meaning the promotion and maintenance of health and wellbeing].

Section 46(2) states that:

> (2) A consent given by a person responsible for, or the guardian of, the patient has no effect:

(a) if the person carrying out or supervising the proposed treatment is aware, or ought reasonably to be aware, that the patient objects to the carrying out of the treatment, or
(b) if the proposed treatment is to be carried out for any purpose other than that of promoting or maintaining the health and well-being of the patient.

The problem with 'promoting and maintaining health and wellbeing' in the end-of-life context

As the previous section demonstrates, all substitute decision-makers in NSW, including the Guardianship Tribunal, guardians, enduring guardians and persons responsible must make decisions which promote and maintain the health and wellbeing of the patient. It has been argued that this phrase cannot include decisions to withhold-or withdraw treatment. In *WK v Public Guardian (No 2)* [2006] NSWADT 121, the NSW Administrative Decisions Tribunal (NSWADT) found that a guardian could not make a decision to withdrawal treatment, as death was not promoting or maintaining health and wellbeing. The patient in question was 73 year old man with end stage kidney disease, advanced heart disease, dementia and bowel cancer, who was receiving haemodialysis. A decision was made by his treating physician, the patient's sister in law and other relatives and friends, to stop the dialysis and give palliative care. However, a friend of the patient, WK, objected to the decision to withdraw treatment and the decision was referred to the NSW Guardianship Tribunal. The Tribunal appointed the Public Guardian as guardian. The Public Guardian, amongst other things, consented to the withdrawal of treatment, a not-for-resuscitation order and palliative care.

WK appealed the decision of the Public Guardian to the NSW Administrative Decision Tribunal (NSWADT). The Deputy President of NSWADT issued a stay on the decision to withdraw treatment, and ordered that further evidence be presented: *WK v Public Guardian* [2006] NSWADT 93. On the return of the application the NSWADT decided that the decision to withdraw dialysis and to refuse 'aggressive' treatment was beyond the power of the Public Guardian. This effectively left the patient to be treated to death, against the wishes of the medical staff, against the wishes of the majority of his family and against his best interests.

There are obvious failings in such an interpretation of the phrase 'promote and maintin health and wellbeing'. It ignores the fact that when a patient is dying, treatment withdrawal and palliative care can substantially enhance a patient's welfare, and, in that sense, promote their health and wellbeing. The interpretation also means that disabled patients who are not competent to refuse treatment will be left with aggressive treatment as the only option and will effectively be battered to death. This simply cannot be the correct interpretation of the Act and since *WK (No 2)* competing interpretations have surfaced.

In *Re AG* [2007] NSWGT 1 (5 February 2007), the NSW Guardianship Tribunal reviewed the findings in the WK matter, and gave a decision which substantially diverted from the findings of the NSWADT. The patient was a 56 year old woman with mild intellectual disability, who was born in Malta but raised in Australia. Both her parents were dead and she lived alone in her own home, receiving support services on a daily basis from a specialist care provider. AG had been diagnosed with a renal tumour with lymphadenopathy. There was also the possibility that she had secondary brain tumours and her prognosis was consequently very poor. Miss AG had a history of refusing medical treatment, including fear of needles. She also refused to acknowledge the existence of the kidney tumour, although she had accepted that she had cancer. The Public

Guardian had previously been appointed to manage AG's care but was now faced with a decision concerning a palliative care plan which included decisions to forego CPR and dialysis. The Public Guardian approached the Guardianship Tribunal for directions on the care plan, given that the WK (No 2) decision seemed to conclude that it was not possible for the Public Guardian to consent to such a plan.

The Tribunal decided that, generally, consent could be given or refused for medical treatment under the *Guardianship Act*, which included palliative care. Palliative care could include treatment limitations, such as the non-provision of treatment, on the proviso that the palliative care promoted and maintained the patient's health and wellbeing. The Tribunal stated at the weight of authority supported the notion that treatment limitation can promote and maintain a person's health and wellbeing, if it prevents futile treatment and if it allows the person to die with comfort and dignity.

The Tribunal also found that guardians with health care functions could be given the power to be involved in advance care planning. The Tribunal also recognised that advance care planning could also be engaged in without the necessity of appointing a guardian with a health care function.

In conclusion, the Tribunal felt that it was necessary for a specific order to be made to give the Public Guardian the power to consent to the proposed palliative care plan, and that could only be done after further the medical investigations mentioned above were completed.

After *Re AG* the NSWADT was given another chance to re-interpret the power of substitute decision-makers under Part 5 in *FI v Public Guardian* [2008] NSWADT 263. The applicant, FI was the mother of DFI, a 24 year patient who had been severely brain damaged in a car accident.FI claimed that DFI was in a vegetative state, although this was disputed by her medical carers. The Public Guardian had been appointed as DFI guardian and had been given powers to make end-of-life decisions. FI requested the Public Guardian to exercise those powers to refuse treatment for DFI. The Public Guardian refused to do so on the basis that such a decision was beyond power, given the findings in *WK (No 2)*. O'Connor J rexamined *WK* and whether decisions to wuthdrawal treatment could promote and maintain health and wellbeing. O'Connor found that:

> 47 In my view, the Guardianship Act.does not seek to fetter a guardian in a way that is inconsistent with the ordinary law. A plenary order bestows on the guardian 'all the functions of a guardian of that person that a guardian has at law or in equity' (s 21(1)(b)). Accordingly, in my view, a specified function in a limited guardianship order should be interpreted in accordance with what is permitted by law or in equity in relation to the kind of conduct the subject of the specified function. The only difference between the rights enjoyed under the law as between an autonomous individual with capacity, and a guardian responsible for a person without capacity, is that the guardian must always act according to best interests considerations whereas the autonomous individual, in the exercise of free will, may make decisions which, objectively, appear to be against his or her best interests...
>
> 49 It would, in my view, be a strange outcome if the order-making powers of the Guardianship Tribunal were to be read down, as compared to the powers available to the Supreme Court in the protective jurisdiction, so as to prevent guardians as substitute decision makers to be involved in the making of care decisions that have elements that

> involve the cessation of medical treatment. The Supreme Court's inherent protective jurisdiction and the Guardianship Tribunal's statutory jurisdiction are both seeking to serve the same end.

After *FI v Public Guardian* the NSWADT considered withdrawal of artificial feeding and hydration in *LE and LF v Public Guardian* [2009] NSWADT 78. In this case the patient was a 47 year old man with post coma unresponsiveness (vegetative state). The Public Guardian had been appointed to take care of the patient's treatment and had decided to not unblock the patient's feeding tube the next time it became blocked. The wife and son of the patient agreed with this decision but the patient's niece and her husband wished to take the patient to China for experimental treatment. O'Connor DCJ said:

> 33 In my view the correct and preferable decision in the circumstances of this case is to affirm the Public Guardian's two decisions. The alternative treatment proposal has little scientific validation, would involve exposing Mr A to increased risks of harm and separate him for a prolonged period of time from his closest family members. The advance care plan including its provision not to reconnect or unblock the PEG tube the next time there is a blockage or other matter warranting consideration of replacement is reasonable in the circumstances. It is consistent with the law, including ethical considerations. Both decisions are consistent with the wishes of Mr A's closest family members.

The effect of these decision is to make it clear that guardians do have the power to refuse treatment, as long as the decision is made in the patient's best interests. However, it remains to be seen whether other persons responsible also have this power. Logically, all the substitute decision-makers in Part 5 of the Act should be subject to the same restrictions and able to exercise the same powers. However, O'Connor J appears to have been very careful to concentrate the wording of the decision on guardianship alone.

If other substitute decisionmakers (such as persons responsible) cannot consent to withdrawal of treatment it will necessitate all cases of withdrawal to go before the guardianship tribunal or the Supreme Court when there is no guardian appointed. When such a provision was initially trialed in Queensland it was removed from the legislation because it was completely unworkable and impractical. NSW should not go down this path and should allow all substitute decisionmakers the power to be involved in these decisions. This would bring the law in NSW in line with Victoria, Queensland, Western Australia and Tasmania.

Proposed solutions

1. *Replace the phrase 'promote and maintain health and wellbeing' with 'promote the best interests of the person'*

An immediate reform which is necessary and appropriate would be to amend the wording of the Act to replace the phrase 'promote and maintain health and wellbeing' with 'promote the best interests of the person.' Alternatively the phrase 'promote the best interests of the person' could be used as an alternative test to 'promote and maintain health and wellbeing.' This is what has occurred in the *Powers of Attorney Act* 1998 (Qld) and the *Guardianship and Administration Act* 2000 (Qld), in Section 12 of Schedule 1 where treatment can be given or withheld if it:

(i) is necessary and appropriate to maintain or promote the adult's health or wellbeing; or
(ii) is, in all the circumstances, in the adult's best interests

The best interests test is a long standing test that is used by judges when they exercise the tradition *parens patriae* jurisdiction. It is true that the best interests test has been difficult to define on occasion. Some judges have simply refused to attempt any general mapping out. In *Re T (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33, 52 Balcombe LJ stated that any attempt to lay down a test would be unhelpful. Similarly, in *Re T (A Minor)(Wardship: Medical Treatment)* [1997] 1 WLR 242 at 254, Waite LJ stated that any generalisations about the test were out of place as each case turned on its own facts and circumstances.

In *Airedale NHS Trust v Bland* [1993] AC 789, the majority of the House of Lords found that the best interests test should be determined by the medical profession in accordance with what a responsible body of medical opinion believed would be in the patient's best interests. This was an adaptation of the the *Bolam* test of medical negligence. The problem with this formulation is the way that the equation of medical assessment with best interests ignores the subjective personal and social dimensions of a person's best interests. Not all English judges were comfortable with this result and the Court of Appeal is later judgments stated firmly on a number of occasions that the best interests test is wider than medical interests: *In re MB (Medical Treatment)* [1997] 2 FLR 426; *Re A (children)(conjoined twins)* [2000] 4 All ER 961, 994 (Ward LJ). In *Re A (Male Sterilisation)* [2000] 1 FLR 426, 555, Butler-Sloss LJ stated that 'best interests encompasses medical, emotional and all other welfare issues.' In *Re S (Adult Patient's Best Interests)* [2000] 2 FLR 389, 400-1, the *Bolam* test was said to be irrelevant to the best interests test, once a decision had been made about the acceptable alternatives for treatment. In light of this change in attitude, judges in England now approach the question of bests interests by drawing up a list of the advantages and disadvantages of the proposed course of treatment: *NHS Trust v Ms D* [2005] EWHC 2439; *An NHS Trust v MB* [2006] EWHC 507

Judges in Australia have done more to provide guidance of the content of the test. In *Re Marion (No 2)*(1992) 17 Fam LR 336 (a case involving the sterilisation of a minor), Nicholson CJ created a checklist of factors to consider in assessing best interests. Those factors include:

(1) The particular condition of the patient which requires the procedure or treatment;
(2) The nature of the procedure or treatment proposed;
(3) The reasons for which it is proposed that the procedure or treatment be carried out;
(4) The alternative courses of treatment that are available in relation to that condition;
(5) The desirability of and effect of authorising the procedure or treatment proposed rather than the available alternatives;
(6) The physical effects on the patient and the psychological and social implications for the patient of:
    (a) authorising the proposed procedure or treatment
    (b) not authorising the proposed procedure or treatment
(7) The nature and degree of any risk to the patient of:
    (a) authorising the proposed procedure or treatment
    (b) not authorising the proposed procedure or treatment
(8) The views (if any) expressed by the carers of the patient:
    (a) the guardian(s) of the patient;
    (b) the relatives of the patient;
    (c) a person who is responsible for the daily care and control of the patient;
    (d) the patient;

to the proposed procedure or treatment and to any alternative procedure or treatment.

The first case to consider the application of *parens patriae* to end of life decisions in Australia was *Northridge v The Central Sydney Area Health Service* (2000) 50 NSWLR 549, the patient, Thompson, had overdosed on heroin and was admitted to the hospital. As he had suffered a significant brain injury from having stopped breathing. It was decided by the medical team treating Thompson that a 'not for resuscitation' order be place on his chart and that he be given no antibiotics after a few days of treatment, as it was believed that Thompson was in a vegetative state. It was claimed that such treatment was futile (see the discussion below). However, Thompson's sister sought a court order over turning the decision, on the basis that there had been a misdiagnoses and that Thompson was recovering. O'Keefe J agreed with Northridge and ordered that all decisions to withdraw treatment be reviewed by him under the *parens patriae* jurisdiction. He was critical of the hastiness of the diagnosis, the fact that the hospital's own policies regarding not for resuscitation orders had not been followed and with the inadequacy of communication between the hospital staff and Thompson's family. His Honour stated at [24]:

> There is undoubted jurisdiction in the Supreme Court of New South Wales to act to protect the right of an unconscious person to receive ordinary reasonable and appropriate (as opposed to extra-ordinary, excessively burdensome, intrusive or futile) medical treatment, sustenance and support. In this day and age ordinary reasonable and appropriate treatment, for a person of the age and condition of Mr Thompson, would extend to the administration of antibiotics and appropriate feeding. The court also has jurisdiction to prevent the withdrawal of such 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.

The courts will not overturn a medical decision when there has been a good faith attempt to seek alternative opinions and those opinions are in agreement about the treatment options. In *Messiha (by his tutor) v South East Health* [2004] NSWSC 1061, where the family of a patient sought a court order for the continuation of life-sustaining treatments. The patient had had a cardiac arrest and suffered severe brain damage as a result. He had a history of heart disease and severe lung disease. There was unanimous medical opinion that the best interests of the patient would be served by the managed withdrawal of treatment. However, the patient's family disputed this and believed that treatment was not futile if it continued to support the patient's life. Howie J decided that the managed withdrawal of treatment was in the patient's best interests. He was swayed by the unanimous medical opinion as to the patient's prognosis, and believed that the treatment was burdensome and futile.

Similarly, *In the application of Herrington; re King* [2007] VSC 151, continued treatment was found to be futile for a patient with hypoxic brain damage and had multiple serious health problems, including kidney failure. She was described as being in a vegetative state. The court found that withholding treatment was in her best interests given the unanimous medical opinion that treatment was futile.

Finally in *Melo v Superintendent of Royal Darwin Hospital* [2007] NTSC 71, the Supreme Court of the Northern Territory refused to order the continuation of ventilation for a brain damaged man. Paulo Melo had been severely injured in a motor vehicle accident, with compromised blood flow to his brain and severe spinal damage. He had a Glasgow Coma Scale rating of 3 (the lowest) indicating extremely low brain function. The hospital treatment team had determined that continued continued ventilatory support was futile. The patient's family disagreed and stated that they believed his eye movements to be meaningful. The treatment team countered by saying that the movement was involuntary and probably caused by spasms from the spinal injury. Further opinions were sought from the Royal Adelaide Spinal Unit, the Royal Adelaide Intensive Care Unit, a visiting neurologist and a visiting neurosurgeon. These all concurred with the decision to cease ventilation. A further opinion was sought by the family but that doctor had not yet seen the patient at the time of the trial.

The judge expressed a real concern with extending the ventilation given all the evidence was against it. He refused to order the continuation of the ventilation on the grounds that there was unanimous medical opinion that it was not in the patient's best interests.

These cases show that while the best interests test is difficult to define precisely, it is an established test which is used in common parlance by both the legal and medical professions. It is one that can be understood by laypeople and it allows decisions to be made regarding treatment withholding and withdrawal. In cases of dispute it provides a known test for the Guardianship Tribunal and the Supreme Court to fall back on. These amendments are need immediately and Parliament should not delay their implementation.

2. ***Engage the NSW Law Reform Commission to review the operation of the* Guardianship Act and its effects on the provision of medical treatment.**

A more substantial review could then occur to investigate whether further changes are necessary and appropriate. Such a review would also be able to take into account recent proposal for uniform approaches to substitute decision making in Australia which are currently before the Australian Health Ministers' Advisory Committee.

I thank the Committee for allowing me to make this submission and I hope it proves useful to its deliberations. I would be more than happy to appear before the Committee should it wish me to answer further questions relating to this submission.

Yours faithfully

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