

ACTS AMENDMENT (CONSENT TO MEDICAL TREATMENT) BILL 2006

Second Reading

Resumed from an earlier stage of the sitting.

HON NORMAN MOORE (Mining and Pastoral - Leader of the Opposition) [5.46 pm]: This is the most interrupted speech that has ever happened, I think. This is about my fourth go now. Hopefully, I will not need a fifth. Previously, I was indicating to the house what a sample living will might be like, in the absence of one being provided by the government. As I indicated, the sample living wills that I had were from the Internet, and I just chose them at random. One living will that I have with me is headed “Sample Living Will Directive to Physicians”. This is one that I think might be easier to deal with than the previous one, in which people had to fill in all the details themselves. It states -

I, _____, being of sound mind, wilfully and voluntarily make known my desire that my life shall not be artificially prolonged under the circumstances set forth below, and do hereby declare:

1. If at any time I should have an incurable condition caused by injury, disease, or illness certified to be a terminal condition by two physicians, and where the application of life-sustaining procedures would serve only to artificially prolong the moment of my death, and where my attending physician determines that my death is imminent whether or not life-sustaining procedures are utilized, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally.
2. In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this directive shall be honoured by my family and physicians as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

Further down in the list it states -

7. I understand that I may revoke this directive at any time.

That sample living will covers a whole range of circumstances that an individual may well find himself in, and under those circumstances be quite comfortable with a decision being made not to prolong life. That description, as I read it anyway, seems to cover most of the conditions that I think a person would seek to have in place before the decision was made to terminate his life or to not extend his life. The last bit about a person being able to “revoke this directive at any time” is important in the context of the legislation currently before the house. As I said, the other night we had a very detailed and excellent address from Hon Helen Morton in which she expressed some concern about the difficulty that a person might have to go through to amend or revoke a living will under the state government’s legislation. Without going into the arguments that she put forward, I will be very keen to hear the response of the minister handling this bill. I have spent as much time as I could thinking about this matter, and I must say that thinking about a person’s death is not a pleasant experience. However, having thought about it in the context of this legislation, there are several things that I would want clarified in the minister’s response and, indeed, looked at in the committee stage of the legislation. How can we make it easy for a person to fill in a living will in the absence of the medical knowledge that one needs to fill in the sample living will that I talked about earlier? Has the government contemplated the notion that people who fill in these sorts of living wills should receive legal or medical advice before they sign them? I raise that because of the complexity of the issues involved. A person who does not understand what the circumstance might be when his living will is put into practice could, when filling out such a form, create a set of circumstances that go against his best interests. I would hate it if someone failed to receive life-sustaining assistance because the form he filled in did not cover all the circumstances that he had in mind, and that, had he filled in the form differently, the outcome might have been different. That is an important part of this issue.

Second, I am concerned about the notion that a person is able to change his mind as often and as readily as he wishes. I, again, come back to Hon Helen Morton’s comments about the difficulties that may be attached to this legislation if a person wants to revoke his wishes. It must be as easy as possible for a person to change his mind and to change his living will so that he is not locked into a particular course of action should his circumstances change. This is quite a difficult issue for members to deal with, because we are dealing with life and death matters, and people have different views about life and death matters. From my own perspective, as far as I am concerned I am ongoing. However, others may not be able to cope with the circumstances that they find themselves in and will be quite comfortable passing on. Everybody’s circumstances are different. I am quite comfortable lending my support to the principle behind the bill, which is to allow people to produce these sorts of documents if they so desire. Heaven forbid that they will ever become compulsory. If we look at experiences in other parts of the world, not too many people have taken advantage of them. The documentation I have from

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the United States suggests that about 20 per cent of Americans have living wills. That figure is quite high, but it is not what the proponents of living wills anticipated when they started promoting them. In the context that this bill represents a choice for people, I support its main principle. However, I look forward with some interest to the minister's explanation about the details of the bill as they have been relayed by Hon Helen Morton and others. Answers must be provided to the questions Hon Helen Morton asked about very important issues. With those comments, I am happy to support the second reading.

HON GEORGE CASH (North Metropolitan) [5.55 pm]: The Acts Amendment (Consent to Medical Treatment) Bill 2006 proposes amendments to three specific acts; namely, the Guardianship and Administration Act 1990, the Civil Liability Act 2002 and the Criminal Code. When considering the substance of the bill, I asked myself the following questions: what are the public policy objectives of the bill as claimed by the government; is there a need for the proposed amendments having regard for the current law; what is the likely practical impact of the amendments; do the amendments achieve the stated public policy objectives; and can the bill be improved?

I will first talk about the public policy objectives as claimed by the government in its second reading speech. When I refer to a second reading speech, I refer to the government's propaganda which, in the main, is used to set out the propositions contained in a bill. However, as we have learnt, a second reading speech does not necessarily reflect what is contained in a bill. The general public policy objectives were stated by the government in its second reading speech, which was given in this house in December 2006. The government claimed that the law in relation to the withdrawal or withholding of life-sustaining measures in circumstances of terminal illness or permanent unconsciousness and the provision of palliative care was uncertain and that it did not provide sufficient protection to health professionals involved in end-of-life decision making and treatment. To that end, I agree with the general proposition advanced by the government. Most people in the community are uncertain about their rights when it comes to withholding life-sustaining measures, so there is a need for clarification in that area. The government also indicated that the principle behind the bill was that of personal autonomy. I understand the government's comments in that regard. The government also stated that the bill would establish a simple and flexible scheme whereby a person could ensure that, in the event of his becoming mentally incompetent and requiring medical treatment for any condition, including a terminal illness, his consent or otherwise to specified treatment could be made clear in an advance health directive and/or alternative treatment decisions could be made by an enduring guardian chosen by the person. The point I make about that is that the bill deals with any circumstance that a person may find himself in. It seems convenient for members to believe that the bill deals only with terminal illnesses. That is not the case, notwithstanding what the second reading speech claims. The government also stated that the bill will clarify the circumstances in which consent can be given or refused in the absence of an advance health directive by a guardian or an enduring guardian. The government stated that the bill seeks to clarify and expand the protection from criminal and civil liability afforded health professionals. The government made it very clear in the second reading speech that the bill will not change the position at common law whereby a health professional is under no obligation to provide treatment that is not clinically indicated. The government also stressed in its second reading speech that the legal position with respect to euthanasia will not change; indeed, it emphasised that the bill will not permit euthanasia. One must measure the second reading speech against the content of the bill and the impact of the amendments on the particular acts that it seeks to amend.

I go back to my first question: is there a need for the proposed amendments having regard for the law? In considering whether there is a need for the bill, it is obviously necessary to consider the law in Western Australia. It is fair to say that the government has correctly advised that no statute deals with the substance of this bill. The question that must be asked and considered is: what are the established common law rights of an individual that allow him to decide the extent of the medical treatment that he wishes to have administered to protect his body from injury or death? In considering that, it is also necessary to recognise that the right to decide the extent of the medical treatment to be administered includes the right of an individual to refuse medical treatment, even if such refusal results in the death of that individual. It is therefore axiomatic that a medical practitioner does not have the lawful right to impose treatment against the will of a patient and that he may be subject to a criminal charge of assault if he treats a patient whilst knowing that such treatment has been refused by the patient. This complex issue potentially has far-reaching effects for not only an individual, but also a third party that might be called upon to provide medical treatment or advise on the extent of the medical treatment desired by an individual. I will later go into some of the issues that are being considered by the courts that confirm our common law rights in Western Australia

Sitting suspended from 6.00 to 7.30 pm

Hon GEORGE CASH: Prior to the dinner break, I was discussing four or five matters that I had looked at in considering this bill; namely, in the first instance: what are the public policy objectives of the bill as claimed by

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the government; is there a need for the proposed amendments having regard to the current law; what is the likely practical impact of the amendments; do the amendments achieve the stated public policy objectives; and can the bill be improved? I had commented on the public policy objectives as claimed by the government. I was dealing with the current law in Western Australia and I was commenting on the common law. The common law, not only in Australia but also as it is well settled in particularly the United States and the United Kingdom, is very clear. In the United States there is a leading case, *Cruzan vs Director, Missouri Department of Health* (1990) 497 US 261. The US Supreme Court was required to deal with the question of whether there was reliable evidence of the patient having desired the withdrawal of life support. There is a very long report in this case. As part of its judgement the court noted as follows -

“At common law, even the touching of one person by another without consent and without legal justification was a battery. See W. Keeton, D. Dobs, R. Keeton, & D. Owen, Prosser and Keeton on Law of Torts § 9, pp. 39-42 (5th ed. 1984).

In that judgement, the court went on to say -

Before the turn of the century, Mr Justice Gray of the US Supreme Court observed that -

[n]o right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.

*See Union Pacific R. Co. V. Botsford, **141 U.S. 250**, 251 (1891).*

The Supreme Court in *Cruzan vs Director, Missouri Department of Health* went on to say in its judgement -

This notion of bodily integrity has been embodied in the requirement that informed consent is generally required for medical treatment.

They made reference to the fact that Justice Cardozo, while on the Court of Appeals of New York, aptly described this doctrine in the following terms -

Every human being of adult years and sound mind has a right to determine what shall be done with his own body, and a surgeon who performs an operation without his patient’s consent commits an assault, for which he is liable in damages.

That is a leading US case with respect to the established common law that deals with a person’s right about agreeing or not agreeing to medical treatment. In 1993 a case in South Australia of F against R 33 SASR 189, the Supreme Court of South Australia recognised at page 193 the following -

the paramount consideration that a person is entitled to make is his own decisions about his life.

In the United Kingdom in the case of *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All England Reports 449, the court upheld the right of a competent patient to refuse medical treatment even if the result was death. In that case, at pages 652 to 653, Lord Donaldson acknowledged the following -

. . . absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered . . . notwithstanding that the reasons for making the choice are irrational, unknown or even non-existent, they rest with the patient.

I wanted to highlight those cases because they establish and state very clearly the common law with respect to a person’s right to control treatment or otherwise for his or her own body.

With regard to the Acts Amendment (Consent to Medical Treatment) Bill, we must ask whether the factors that are being taken into account justify the need for statutory intervention in this particular area. It is fair to say that there is confusion among community members of their common law rights in attaining their actual wishes in end-of-life decision making and treatment. That is an established fact, but that in itself does not mean there should be a statute on the matter; perhaps more education is an answer.

It is the government’s view, as I suggested earlier, that those who provide medical treatment should have greater certainty and protection from criminal and civil liability when involved in end-of-life decision making and treatment. That is something that I agree is desirable. The proposition, therefore, in the bill is to allow a person who has attained the age of 18 years and is mentally competent to make a declaration about the requiring of medical treatment or about any condition - I stress, any condition - including a terminal illness, or consent or otherwise to specify treatment in an advance health directive.

One of the things that concerns me about this bill is that, unlike similar legislation in both other Australian jurisdictions and overseas, it does not appear to require the maker of an advance health directive to consult a

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medical practitioner about his condition or likely condition. I term this ignorance of the person's own medical condition or likely condition to be uninformed consent, when dealing with future possibilities.

If we look at the likely practical impact of the amendments, it is clear that the common law rights of the individual are well established, and this bill does not seek to override the common law rights. The existing common law directives will continue to be binding in Western Australia. If this bill becomes law, a two-tiered system will operate in Western Australia. That is not an unreasonable proposition. The effect of the two-tiered system will enable an individual to choose either option. In my view, the most significant difference between the two options will be the requirement for an individual to choose the statutory option to comply with the statutory requirements set out in the bill. The question is whether the statutory requirements proposed by the government are adequate.

In considering specific areas of the bill - for instance, proposed part 9B, division 1, which deals with advance health directives - it must be understood that the advance health directive in this bill is intended to be made in contemplation of the maker becoming mentally incompetent and requiring medical treatment for any condition. I say "any condition" because there seems to be some belief that the directives are only for some very specific areas; they are for any condition. The bill is very broad; it is broader than most other legislation in Australia, and, indeed, many overseas jurisdictions.

The following point greatly concerns me. Although the bill can be amended to improve the situation, the bill has no requirement for the person making the advance health directive to be adequately informed of the consequences of the operation of the directive, or for the maker to be suffering from a particular condition, or for a person providing medical treatment to inform the patient of the substance of his illness or of the nature of potential treatment. All this bill requires is that the maker of an advance health directive be 18 years old, have full legal capacity and that the treatment decision be made voluntarily and without inducement or coercion. Those requirements do not necessarily reflect informed consent. The bill almost implies consent and a certain level of knowledge if a person signs the directive, is 18 years of age and is competent. That is totally wrong, because the patient would not necessarily have that actual knowledge. The effect of the failure to ensure that a maker is adequately informed before signing an advance health directive will be that the maker will fly blind in respect of the medical options that may be available now or in the future to treat their specific condition.

The failure of the amendments to require the maker to be reasonably informed may create a circumstance by which treatment administered, or ceased to be administered, based on the advance health directive may be based on flawed assumptions by either the maker or the person providing the medical treatment to the maker. This aspect of the bill can be improved; it has to be improved because currently informed consent is not a prerequisite of this bill. Informed legal consent is a prerequisite of other legal agreements - I am thinking of commercial contracts and other such matters - but such consent is not necessary in this case of advance health directives.

Some interesting cases have arisen in respect of contract law in which people have borrowed money from banks, and the banks have not fully advised the borrowers of their rights or responsibilities. In some cases this has caused married women who signed because their husband invited them to sign, rather than signing through understanding the contract, to be able to go to court and say that they were never properly informed and never gave informed consent; therefore they avoided their liability. If it is good enough to have informed consent for a commercial contract, one, at the very least, should have informed consent when drawing up an advance health directive that is aimed at providing or not providing medical treatment for a patient in certain circumstances.

Another issue of concern is that a number of other Australian jurisdictions have pro forma documents that form part of schedules to acts that are required to be completed by the maker of the advance health directive. The government could argue that it is up to the individual to find his or her own words. However, rather than have a multitude of differently worded advance health directives, it would be more convenient to have a standard form that can be amended to suit individual circumstances. It is obviously critical that an individual advance health directive properly expresses the true intentions of the maker. I accept that some amendments may need to be made, but it would be a lot more helpful to an individual to know that the document he or she is filling out has been considered and that no unexpected loopholes are likely to be found.

I made the point that if a person seeks to borrow funds, that person must give informed consent; that is, informed consent must be part of the contractual agreement. That is not the case in this bill, and there is huge opportunity for improvement in that area. We can deal with particular provisions in committee, but I raise these issues because I could not vote for the bill in its present form. We have no intention of voting for it at all because it is vague and uncertain and could lead to tragic circumstances for a patient who was not provided with additional medical advice from a health operative or a medical practitioner. For instance, proposed section 110S in part 2 of the bill appears to be loosely drafted and has the potential to create uncertainty; as a result, a number of questions need to be understood and answered in this house. The same applies for proposed section 110S(3),

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which deals with circumstances in which a patient nominates when the directive will not operate. The question is: who makes the decision regarding the maker's change of mind or the maker's change of circumstances? The same issue arises again with proposed section 110S(6). Proposed section 110RA refers to the proposed register. The bill generally states that a register will be established. However, the bill does not state that advance health directives are required to be registered. The bill does not provide any information as to whether the register is intended to be open to the public or whether it is intended to be available only to a limited group of people - for instance, the enduring powers of attorney or the immediate family of the maker. Those issues provide opportunities for improvement.

Attempting to improve the bill through amendments on the run in the committee of the whole in the chamber would not be wise. It would be better for the bill to be referred to a committee so that members can sit down and work through it and consider examples provided by other legislation in operation both elsewhere in Australia and overseas. For instance, in proposed part 9C, proposed section 110ZD deals with persons responsible for patients and, like the amendment to the Criminal Code, appears to stand alone. I would like the minister in due course to confirm whether this section is dependant on the existence of a valid advance health directive. If members read part 4 of the bill, they will see that it deals with proposed amendments to the Criminal Code, one of which is to section 259 of the Criminal Code. Some members of the community believe that proposed amendment to the Criminal Code is consequential upon the decision to agree to advance health directives. However, if members read the bill carefully, they will see that it is clear that the proposed amendment to section 259 of the Criminal Code stands alone in its operation and is not a consequence of the other proposed amendments contained in the bill. Although it may be convenient to claim that there is a requirement emanating from the other proposed amendments in the bill to cover people who provide persons administering or ceasing to administer medical treatment with a defence should they be charged with a criminal matter, it is certainly not an amendment that relates only to end-of-life decision making and treatment.

I am quite sure that doctors and health workers in the community are keen that section 259 of the Criminal Code be amended; however, similar acts around Australia contain very clear statements that a person who assists in a suicide will continue to be liable for a criminal offence. I do not know whether members consider that we would be stating the obvious if we sought to ensure that matters regarding suicide and other related issues also appeared in this bill, or whether they are satisfied that the Criminal Code in itself already covers that sort of thing and that including it in this bill may be duplicating the situation. However, I accept that the proposed amendment to section 259 of the Criminal Code will clarify the liability of persons administering or ceasing to administer medical treatment and that it is no doubt dear to the heart of many medical operatives. Persons administering or ceasing to administer medical treatment will be required to show that they acted in good faith and that their actions were reasonable, having regard to the patient's state at the time and to all the circumstances of the case.

In respect of the question of whether the bill can be improved, I would argue that although the bill does not derogate from the common law rights of the individual, there is an opportunity in some cases to state the obvious without diminishing the intent of the bill. For instance, the provisions in Queensland are contained in the Powers of Attorney Act 1998. In that act the advance health directive is required to include a certificate signed by a doctor stating that at the time of the making of the advance health directive, the maker appeared to the doctor to have the required capacity. That is a very relevant consideration. Again, in the Queensland legislation there is provision for a direction to withhold or withdraw a life-sustaining measure. However, it states that that direction cannot operate unless one of the following provisions applies. I do not want to go through the Queensland act word for word, but section 36(2) in part reads -

- (i) the principal -

Meaning the maker of the directive or the patient -

has a terminal illness or condition that is incurable or irreversible and as a result of which, in the opinion of a doctor treating the principal and another doctor, the principal may reasonably be expected to die within 1 year;

- (ii) the principal is in a persistent vegetative state, that is, the principal has a condition involving severe and irreversible brain damage which, however, allows some or all of the principal's vital bodily functions to continue, including, for example, heart beat or breathing;

There are a number of exceptions, and only one of these matters needs to apply to a patient. It continues -

- (iii) the principal is permanently unconscious, that is, the principal has a condition involving brain damage so severe that there is no reasonable prospect of the principal regaining consciousness;

It goes on. It states various specific circumstances that must be in operation before one can withdraw or withhold life-sustaining measures.

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The Tasmanian legislation contains a form for consent to medical treatment. Clause 4(2) of the bill contains a provision for the refusal of treatment for current conditions. It states -

If a medical practitioner and another person are each satisfied -

- (a) that a person has clearly expressed or indicated a decision -
 - (i) to refuse medical treatment generally; or
 - (ii) to refuse medical treatment of a particular kind -

It then goes on to provide for certain circumstances. The point I make is that at least one person certifying the document must be a medical practitioner, there must be one other person, and both must be satisfied of certain provisions.

I should acknowledge that in Tasmania the bill before the house was read to the Parliament last year but does not appear to have progressed past the original reading. Again, there are schedules in the Tasmanian legislation that set out in clear terms the form for the refusal of treatment certificate, and the medical practitioner is required to sign the form in respect of anticipatory grants or refusal to consent to medical treatment. Clause 5(1) of the Tasmanian bill states -

A person of or over 18 years of age may, while of sound mind, give a direction under this section about the medical treatment that the person wants, or does not want, if he or she is at some future time -

It goes on to set out particular circumstances, for example -

in the terminal phase of a terminal illness, or in a persistent vegetative state; and

It goes on to set out more conditions, for instance -

incapable of making decisions about medical treatment when the question of administering the treatment arises.

Again it requires a medical practitioner to certify the certificate.

The South Australian act is the Consent to Medical Treatment and Palliative Care Act 1995. Section 3 of that act sets out the objectives, and states -

The objects of this act are -

- (a) to make certain reforms to the law relating to consent to medical treatment -
 - (i) to allow persons of or over the age of 16 years to decide freely for themselves on an informed basis whether or not to undergo medical treatment; and
 - (ii) to allow persons of or over the age of 18 years to make anticipatory decisions about medical treatment; and
 - (iii) to provide for the administration of emergency medical treatment in certain circumstances without consent; and

It then provides some additional provisions that I will not go into at the moment. However, the critical point I make about the South Australian act is that the decision must be made on an informed basis, and I think that is one of the great failings of the current bill in its present form. The Victorian legislation, the Medical Treatment Act 1988, states under the heading "Refusal of treatment certificate" -

(1) If a registered medical practitioner and another person are each satisfied -

- (a) that a patient has clearly expressed or indicated a decision -
 - (i) to refuse medical treatment generally; or
 - (ii) to refuse medical treatment of a particular kind -
for a current condition; and
- (b) that the patient's decision is made voluntarily and without inducement or compulsion; and

I underline the following -

- (c) that the patient has been informed about the nature of his or her condition to an extent which is reasonably sufficient to enable the patient to make a decision about whether or not to refuse medical treatment generally or of a particular kind (as the case

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requires) for that condition and that the patient has appeared to understand that information; and

(d) that the patient is of sound mind and has attained the age of 18 years -

the registered medical practitioner and the other person may together witness a refusal of treatment certificate.

The point I want to make is that this involves the question of informed consent. Some of the other relevant legislation requires a medical practitioner to certify that he or she has advised the maker of an advance health directive, firstly, of that person's condition, so that he or she fully understands the medical condition from which he or she is suffering; secondly, the person's likelihood of survival; and, thirdly, the various treatments that may be available at present or might be anticipated into the future. It is all about informed consent. As I said, if informed consent is required for a person to borrow funds from a finance company, and the failure of providing informed consent is sufficient to void that person's liability to repay those funds, it seems to me that, at the very least, informed consent should be required before somebody is able to sign a valid advance health directive. We are dealing with a very serious matter. We are also imposing obligations on the appointee under an enduring power of guardianship. The appointee under an enduring power of guardianship is entitled to know the actual medical state of the maker of the advance health directive and also what treatment is available and the likelihood of success of that treatment before he or she makes a decision based on the instructions that he or she has been given about refusing treatment.

I raise those matters in the hope that the bill can be improved. As I have already suggested, in my view the bill is vague and uncertain. It could lead people into temptation and could have very serious consequences for not only the maker of the advance health directive but also, in due course, an appointee under an enduring power of guardianship. The bill could be improved without great difficulty. In fact, the question that keeps coming back to me is: why does this bill attempt to operate without informed consent? That seems to be a basic requirement. It is almost as though other acts of Parliament from Australia and perhaps overseas were researched and then stripped down in a manner that was totally unnecessary.

I earlier noted that the Australian Capital Territory also has an act that deals with advance health directions. Section 11 of the Medical Treatment (Health Directions) Act 2006, headed "People with decision-making capacity to be informed of alternatives etc", states -

- (1) This section applies if -
 - (a) a person has made a health direction; and
 - (b) the person has decision-making capacity.
- (2) Before complying with the health direction, a health professional treating the person must take all reasonable steps to ensure that the person has been informed about -
 - (a) the nature of the person's illness; and
 - (b) any alternative forms of treatment that may be available; and
 - (c) the consequences of the available forms of treatment; and
 - (d) the consequences of remaining untreated.
- (3) The health professional must not give effect to the health direction unless the health professional believes, on reasonable grounds, that the person -
 - (a) has understood the information provided under subsection (2); and
 - (b) has weighed the various options; and
 - (c) after weighing the options, has confirmed the decision -
 - (i) to refuse medical treatment; or
 - (ii) to have medical treatment withdrawn.

That is a variation on the need for the maker of a health direction to be informed. In the Northern Territory, the Natural Death Act 1988 provides a power to make a direction. It states in section 4 -

- (1) A person of sound mind who has attained the age of 18 years, and who desires not to be subjected to extraordinary measures in the event of his or her suffering from a terminal illness, may make a direction in the prescribed form.

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I underline that the direction is to be made in the prescribed form. That is not provided in the bill before the house. The section continues -

- (2) A direction under subsection (1) is of no effect unless witnessed by 2 witnesses who have attained the age of 18 years, neither of whom is the medical practitioner responsible for the treatment of the person.

Subsection (4) states -

This section does not derogate from any duty of a medical practitioner to inform a patient who is conscious and capable of exercising a rational judgment of all the various forms of treatment that may be available to the patients' particular case so that the patient may make an informed judgment as to whether a particular form of treatment should, or should not, be undertaken.

Again, the emphasis is on informed consent; that is, actual knowledge rather than implied knowledge or no knowledge whatsoever.

There is great scope to improve the bill. There is no doubt, and it is well and truly established, that individuals have a common law right to refuse treatment even if the refusal of that treatment would cause their death. That is an absolute right of every individual. This bill does not take away from that right but because it is to be recognised in statutory form, it is absolutely critical that we ensure that anyone who makes an advance health directive makes it with certain knowledge of their condition and the likelihood of the success or otherwise of treatment for that condition. We must also ensure that medical practitioners are not able to withdraw life support unless they are satisfied that they are following a particular health directive and that that directive was the result of actual knowledge of the medical condition being suffered by the maker of the directive. As I said, there is a huge opportunity to improve the bill. I hope that if it goes to a committee, those improvements will be made.

HON DONNA FARAGHER (East Metropolitan) [8.08 pm]: The Acts Amendment (Consent to Medical Treatment) Bill is indeed difficult and somewhat complex legislation. Perhaps it is also true to say that it touches each and every one of us in one way or another. While it is important to step back from the emotive side of the debate, there can be no doubt that a bill such as this does make us think of those within our community who may be suffering or of loved ones who recently passed away, and indeed makes us all think about what the future may or may not hold. End-of-life issues are extremely challenging. Every day, as others go about their daily lives, there are people living in homes, hospices and hospitals who, through illness or accident, are unable to make decisions for themselves. Often, their family members are left, at times, to make very difficult decisions. In saying that, I am conscious of those in our community who have taken the time to write to me to tell me of their family's story, as well as various associations who have contacted me about this legislation.

In reading the minister's second reading speech, I note that the primary purpose is, and I quote -

A person who is 18 years of age or over and has full legal capacity will be able to make and register an advance health directive containing treatment decisions in relation to his or her future treatment. A treatment decision will operate in respect of the treatment to which it applies at any time when its maker is unable to make reasonable judgments about that treatment. Provided that a person makes a sufficiently clear decision that is applicable to the clinical circumstances that have arisen, a health professional will be obliged to comply with the decision.

With respect to the notion of euthanasia, the speech states -

... the legal position in relation to euthanasia is not to be changed, and it is to be emphasised that the bill will not permit euthanasia.

I am broadly supportive of the bill's intent. In principle I believe that a person, particularly one who has a terminal illness, who wishes to prepare an advance health directive should be able to do so. Importantly for me, the directive must be made voluntarily and without inducement or coercion. In this regard I note that, under the formal requirements within the bill, among other things an advance health directive is not valid unless the directive is signed in the presence of at least one person who is authorised by law to take declarations. In my view, this is an important requirement. However, I am keen to ensure that any unintended consequences are identified and carefully scrutinised, and improvements made to the legislation where necessary. I note that the Legislative Assembly made a number of amendments to the bill. While I will obviously not reflect on the debate in the other place, it is clear from the clauses contained in the bill that is currently before us that a number of amendments have already been made. They include new clauses relating to urgent treatment after attempted suicide and some matters relating to the operation of an advance health directive, particularly when the directive is made more than 10 years before the time that the treatment decision would otherwise operate. These were not included in the original bill.

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I do not intend to speak for a significant time on this bill as a number of issues have already been canvassed. A number of significant concerns have already been raised by members in this place, and they should all be carefully considered. I will outline a couple of examples. One is the notion of the compulsory registration of a directive. That is something that should be very closely examined. I also mention the role of a medical practitioner in assisting with the making of a directive. Hon George Cash has outlined that quite fulsomely with the notion of informed consent. Like Hon Robyn McSweeney and Hon Norman Moore, I would like to see a copy of the proposed pro forma directive so that I can make a better judgement about what it will or will not include, its complexity and the like. We need to see that directive; we need to see what the standard is going to look like so that if someone is going to utilise this form of directive we will know what it will contain, what people will be advised and what they will not be advised.

As I have said, I will not go into the other issues that have been extensively canvassed by other members. Hon Helen Morton and Hon Barbara Scott have identified a number of concerns. They are valid concerns that need to be looked at. As I said before, I am keen to ensure that unintended consequences from this bill are properly identified, carefully scrutinised and addressed. With those very brief comments, may I conclude by saying that I support the principle as outlined in the minister's reading speech, and I will support the second reading. However, I will follow the committee stage very closely, which is where the concerns that have already been raised - no doubt there will be more before we come to a final vote - will be debated and scrutinised more fully.

THE DEPUTY PRESIDENT (Hon Ray Halligan): Order! Before I call the next member, may I remind members to look at standing orders 77 and 78 and bring them again to members' attention. The amount of audible conversation in the chamber makes it difficult for both me and Hansard to hear the member with the call. I ask members to desist.

HON SALLY TALBOT (South West - Parliamentary Secretary) [8.16 pm]: I will not take up much of the time of the house tonight but I want to indicate my support for this bill. It is one of the challenges of bringing argument to a place like this that one learns to evaluate both sides of an argument. One has to be able to see both sides of an argument to make a contribution that has some merit and substance to it. I have followed this debate with considerable interest. If I have not been able to be in the chamber to listen to members, I have followed their contributions by reading *Hansard*.

It is worth pointing out the challenge that we set ourselves when we try to deal with a piece of legislation to give statutory effect to principles like the right to self-determination and the right to freedom of choice, and to enshrine principles like respect for the individual. It seems to me that we are dealing not so much with grey areas. I do not want to suggest that for one moment, because people clearly have very firm and well-reasoned arguments for taking the positions they have taken in these types of debates. In dealing with things like freedom of choice and respect for the individual, the essence of a good piece of statutory direction in legislation will be things like simplicity and flexibility. It seems to me that we have gone a very long way towards achieving both simplicity and flexibility in putting this legislation together. That is the basis of my support for it.

The other point I make is that we are dealing with an area that, certainly for the past century or so, we as a community have found very hard to talk about. Just as our Victorian predecessors found it very difficult to talk about sex - we seem to have overcome that particular difficulty - we now have a great deal of difficulty in talking about death and dying. It seems to me that a piece of legislation like this will go a long way towards giving people the language in which to have conversations with people for whom they care and to talk about what might happen down the track, and to deal with some of the important decisions which, after all, will not only result in the death of a person, but also inexorably change the lives of the people who care for him. That seems to me to be a very healthy thing to be doing. I keep coming back to that point in following arguments, particularly from honourable members opposite, about some of the merits of having this type of debate and framing this type of legislation so that we can introduce some of the fundamental principles, such as freedom of choice, into the lexicon of people's conversations with the people they love and care about.

I will go through some of the background to this bill. It already has been well canvassed by members on both sides of the chamber, and I do not want to take up the time of the minister who will respond to the arguments put by members of the opposition. There are three elements of the bill: the provision for advance health directives; the provision for the appointment of an enduring guardian or guardians; and the concept of a substitute decision maker, who is a person responsible for making decisions on someone's behalf. Most of these issues have been well canvassed in the debate so far. However, I will make a particular point. The Minister for Health and the government must be commended for embracing the concept of enduring guardians. Members have referred to various personal experiences and a number of anecdotes have come to our attention during the course of the debate. However, having cared for a couple of people who have been very close to me and who have died, I understand that the concept of enduring guardians is a quite powerful addition to this debate regarding people taking personal responsibility for the way that they are treated and die. Being prepared to devolve some

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decisions to a loved one is a mark of particular affection and love for that person. It is a recognition that one might well reach a point in one's life when it is more important to allow the decision maker to make a decision on one's behalf that will be right for the decision maker rather than allow only what one has already determined to be done. It will be very interesting to see how that plays out when this bill is enacted.

The provision of having a person responsible to make treatment decisions on behalf of a patient is also a very innovative way of approaching these matters. In a sense, the bill provides for a sliding scale. In the absence of an advance health directive and in the absence of an enduring guardian, spouses, de factos, children, parents, siblings and carers are able to make determinations on behalf of someone with whom they feel a connection. It seems to be a very important step forward to put in place by this legislation a system whereby the first order of decision making rests with the individual. I do not like to call the individual a "patient" because the key to this legislation is that people make these decisions before they become a patient. The responsibility rests with the individual and the decision making devolves to an enduring guardian. If that is not in place, it then devolves to a guardian, who is the person appointed by the State Administrative Tribunal in the absence of the previous two provisions, or to the person who is responsible. By putting in place these kinds of measures, we have set the parameters for people to feel empowered to make these important decisions.

I listened to some of the contributions of members of the opposition, and it is evident that the question that keeps being raised is whether this legislation is actually needed. I have talked about seeing both sides of the argument, and that has been very well expressed. We have had a very considered debate in this place so far. However, in supporting this legislation, I will cite two reasons why, in the end, I come down on the side of supporting it rather than opposing it. The first reason concerns the question of whether the legislation is needed. As with many of these so-called "life questions" - the definition of which I believe is getting broader than was originally intended, but that is the subject of a debate for another occasion - we often seem to be forced into a position whereby the question is whether we allow this to happen or whether we try to stamp it out and minimise it. That certainly is the case in the debates on abortion and prostitution. In the case of end-of-life decisions regarding medical care, the reality is that because humans are the kinds of creatures that we are, people will always give this matter some thought. I am not saying that everyone does it, but there will always be people who want to talk to their carers and medical professionals about what they would like to happen to them at the end of their lives. As has been mentioned several times during the debate, this has been the case for some time and the medical profession has dealt with it in its own way. However, if we are to give real credence to the respect that I think is due to the medical profession, particularly in these types of situations of very high stress when important demands are made on the profession, we must clarify the legal position. We must afford sufficient protection to the medical profession to enable it to make decisions, which I readily concede it is already making but without the degree of protection that many of us consider to be necessary. That is the first reason why I ultimately support this bill.

I was very struck by a letter that I received from Geoffrey Dobb, the president of the Australian Medical Association WA, which is dated 6 June 2007 and states -

I am writing to let you know that the Association supports the general thrust of the above Bill. Importantly, it addresses a number of current concerns over the potential exposure of medical practitioners in areas such as palliative care and intensive care, caring for and providing pain relief to patients during terminal phases of their illness. In the past, there has been concern of potential exposure under the Criminal Code to medical practitioners providing, for example, pain relief during end of life processes.

The Bill also seeks to provide greater clarity in respect to consent to medical treatment, and thus has the potential to greatly assist health professionals seeking to provide care and treatment in accordance with patients' informed wishes. Importantly, whilst there have been some suggestions to the contrary, the Bill does not constitute a move towards euthanasia or physician assisted suicide. The Bill confines itself to clarifying the existing law and the rights of the patient to consent in advance to either the provision or non-provision of treatment. This is consistent with Common Law principles of consent, which are predicated on the right of the patient to autonomy and not to be trespassed upon in the absence of consent or in emergency situations where they have not clearly directed that treatment not be administered.

For your information, I enclose a copy of the AMA's position statement of care for the severely and terminally ill patients.

In closing, I would emphasise that this particular Legislation is very important, from the Medical Profession's point of view, in resolving uncertainties and respecting the autonomy of patients to consent or refuse procedures or interventions.

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I refer anyone who considers this bill to be euthanasia by default to the position statement of the AMA, which makes it very clear that that is not the case.

Another reason I indicate my support for the bill and dissent from the arguments put by the opposition is that in these cases of legislation I cannot buy into the slippery slope argument. I have already suggested that we are dealing with a situation whereby we must formalise protection for the medical profession because people already want to determine for themselves matters about medical treatment at the end of their lives. The slippery slope argument is all too easy. It is the "road to ruin and the end of society as we know it" argument. That argument does not have any kind of intellectual validity. This is very well considered legislation that looks at the current situation and the kinds of choices that people want to make for themselves and the kinds of principles that they want to enshrine in their lives. We have very carefully thought through how some of that should be put into a statutory framework. I commend the drafters of the legislation and the minister for having taken this sensitive approach.

I also wanted to draw the attention of members to another letter that I received. Like many members, I have received a lot of correspondence. One particular letter I want to single out is from Don Keene, the president of the Peel Region Branch of the Association of Independent Retirees. I draw members' attention to this letter because the Association of Independent Retirees is a worthwhile body, and it is not known for its radically left-wing points of view any more than the AMA is. Anybody who is worried about this slippery slope argument and the road to ruin would be well advised to talk to some of these groups that are writing to us with what I consider to be very well thought out arguments. The text of the letter is as follows -

The Members of the Peel Branch of the Association of Independent Retirees (A.I.R.) Ltd. are aware that a Bill to legalise Advance Care Directives (Living Wills) in W.A. will shortly be debated in the Legislative Council.

The name of the bill is slightly different in this house. It continues -

Professor Colleen Cartwright of Southern Cross University was a Speaker at our recent National Conference in Ballina, NSW. Professor Cartwright was emphatic on the need for W.A. to join most of the other States in providing this legislation. She also warned of problems clouding the debate with such issues as confusing Advance Care Directives with permission for euthanasia.

At our last meeting our Members were unanimous in their support of this Bill - on the understanding that it will allow people to make a Living Will should they so desire. I have been asked by the Members to seek your support when this legislation is considered.

I will end on that note, reaffirming, once again, my support for this bill.

HON KEN BASTON (Mining and Pastoral) [8.32 pm]: I have listened to the debate on the Acts Amendment (Consent to Medical Treatment) Bill so far. This legislation is dear to many of us who have seen friends and close family in suffering situations, often bedridden for months or years without being able to make a decision about their lives. I was involved in a situation in which one side of my family was for continuing life support and I was against it because I could see no quality of life. I certainly support the intent of the bill. However, there are many unanswered questions in the legislation. I found many issues in the explanatory memorandum a little disturbing. I looked at the legislation that some of the other states had in place. Many of them had various types of acts that alluded to similar intent. South Australia has the Consent to Medical Treatment and Palliative Care Act 1995. That act refers to an anticipatory grant refusing consent to treatment. It is effective only for patients in the terminal stages of a terminal illness or in a persistent vegetative state; that is, patients must not be competent to make decisions. The Australian Capital Territory has the Medical Treatment Act 1994. That act mandates for a directive that refuses treatment generally or of a particular kind. It does not cover refusals of palliative care. The Northern Territory has the Natural Death Act 1988. It is effective only in the event of terminal illness, defined as illness, injury or degeneration of mental or physical faculties such that death would be imminent if extraordinary measures were not taken. Extraordinary measures are procedures that are intended to prolong life by using artificial means. New South Wales does not have direct legislation for advance directives, but it does have a Guardianship Act, which allows for the appointment of others who can make decisions when the person is no longer competent. It allows for an appointed person to give consent on behalf of that person. Tasmania also does not have direct legislation, but it does have a Guardianship Act. Queensland has the Powers of Attorney Act 1998. Directives cannot operate unless the person has an incurable illness or condition and is not expected to live for more than one year, is in a persistent vegetative state, or has a severe illness with no reasonable prospect of living unless with continued life support. I found the state legislation interesting. One of the things that came to my mind is whether legislation that applies to Western Australia also applies when one travels to other states, or whether another act takes over when one is in another state. These are questions that I will certainly be asking when we get to the committee stage.

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When I was looking at what other countries did, I found that it is only in the past two years that Britain, France and Spain have had any form of advance health directive. I found that interesting, as I thought those countries would have been more advanced in this type of legislation. At present, Italy is very much grappling with this issue. I was interested to note whilst doing some research that when Pope John Paul II was dying of complications of Parkinson's disease in 2005, he refused to return to hospital from his Vatican quarters, rejecting interventions such as breathing machines and kidney dialysis. He was dead a day later. It is a problem around the world, with religion etc playing a role in people's decisions, and it can be very difficult for family and friends.

I found Queensland's advance health directive form to be the most palatable. I also looked at the Canadian form. I found that fairly simple but probably not very conclusive. The Queensland form comes under the Powers of Attorneys Act 1998. It is very clearly set out. I presume that under this bill, there will be regulations. We will not know a lot about those until after the bill is passed. There are many unanswered questions. I will run through the Queensland form briefly. Under "What is an Advance Health Directive?" it states -

You may wish your directive to apply at any time when you are unable to decide for yourself, or you may want it to apply only if you are terminally ill.

There are also headings entitled, "What do I need to consider before making an Advance Health Directive?", "Can I cover all possible health-care decisions in this form?" and "Can I change or revoke my Advance Health Directive?" The Queensland model suggests that people review their directive every two years. I notice in the bill that proposed section 110S(4) of the Guardianship and Administration Act stipulates a figure of 10 years. I could not support a figure of 10 years; it is far too long. I would rather a term in the order of five years. Quite a change of attitude can take place in 10 years, and we could all forget about the directive and never get around to reviewing it. If we know it is 10 years, we would tend to let it go on for longer and forget that we have not made the changes we may have wanted. Someone who at age 20 thought that he would not want to live if he ended up in a wheelchair might change his attitude over 10 years as he becomes more mature.

The pamphlet sets out who is to be involved in preparing the advance health directive. It involves three people. The witness must be at least 21 years of age, not 18, and must be a justice of the peace, a commissioner for declarations, a lawyer or a notary public. He must not be the attorney involved, and must have no connection with him whatsoever. The document is required to be kept in a safe place, or left with a solicitor. I note that the amendments to the bill provide for a register. Where will that register be kept? I presume it will be somewhere in the medical profession. I also note that the State Administrative Tribunal is to be involved in the legislation; changes are being made to include it. I was a little amused by that, bearing in mind that it takes the State Administrative Tribunal a minimum of 21 days before it conducts a hearing, so I wonder where it fits in. The time frame for making these decisions would be a little delayed, but I suppose the SAT would be used only in the event of a dispute.

The first section of the Queensland form is to be filled out with the person's personal details. It emphasises that the directive should never be used if the person has the capacity to speak for himself, or if there is evidence that the directive has been revoked. There is a very good safety net of questions, which should have the effect of teasing out the direction that the person wants to take. The next section deals with terminal, incurable or irreversible conditions. It then defines those three terms very succinctly, along with the terms "permanent unconsciousness", "persistent vegetative state" and "palliative care". If this bill becomes law, I would like a very similar format to be used in Western Australia. It is self-explanatory, and people can study it and go through it step by step. For instance, question 9 covers whether a person who is permanently unconscious wants cardiopulmonary resuscitation. There is a choice in every case; a box to be ticked indicating whether a person wants or does not want a particular procedure. The form concludes with a tissue donation section, which I find quite interesting. It is probably something that can be added to the Western Australian form. There is a section for a personal statement, a doctor involvement form, and an enduring power of attorney for personal health matters. Everything is stated very succinctly. The Canadian form is not as directive as the Queensland model. I hope that the Western Australian model results in a document that is similar to the Queensland form. If it is to work, it must be kept simple.

I note that the bill contains protection for the medical profession. That is very necessary, because in this day and age, if there is any grey area, and a chance for a disgruntled relative to sue, then that will happen.

I have looked at this bill with interest, and I think it has merit. Its intent certainly has merit. The bill does not, however, seem to cover the need for family members to know that a living will exists, although it is rather hard to have that written down anywhere.

In summing up, I believe that an advance health directive should be reviewed at regular intervals. As I said, the Queensland model is two years. This bill allows for 10 years, but I would accept a five-year interval as an

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absolute maximum. Provisions are needed to protect health professionals involved, and they are included. The bill provides that a living will must be made during a period of stable health, and will take effect only when a person can no longer understand and appreciate treatment choices. We must ensure that the definitions in the bill allow for the latest interpretations possible. The document I have been referring to, based on the Queensland model, would have to be updated regularly as well. That is why there should be a five-year review period, so that the documentation can be brought up to speed. I have covered the directives that need to be made to the families. If we sort out a few problems during the committee stage, I believe we can come up with a piece of legislation that will be useful for family decisions and for the medical profession into the future.

HON MATT BENSON-LIDHOLM (South West) [8.48 pm]: I will take a few moments to comment on the Acts Amendment (Consent to Medical Treatment) Bill 2006. I agree with much that has been said so far, and note the general support for the intent of the legislation. Certainly, what Hon Ken Baston said indicates that that very much applies to him. I say this particularly given that most members can quote examples involving friends and relatives when a decision on medical treatment has been an issue. That has certainly been the case in my family. I certainly support the bill, and although I do not wish to go over ground already covered, I wish to comment on a number of issues, particularly what I consider to be the rationale for the bill, my interpretation of some of the more significant issues, the position of the Australian Medical Association WA, which has already been covered to a certain extent by Hon Sally Talbot, and my concern about making decisions early in life and not revisiting such decisions until it becomes too late.

I will commence by quoting from Hon Sue Ellery's second reading speech, because what she said highlights the fact that this bill is both timely and necessary. The speech reads, in part -

Western Australia presently has no legislation providing for advance health care planning in the event that a person loses the capacity to make his or her own decisions regarding medical treatment. Furthermore, the law in relation to the withdrawal or withholding of life-sustaining measures in circumstances of terminal illness or permanent unconsciousness, and the provision of palliative care, is perceived as uncertain and as not providing sufficient protection to health professionals involved in end-of-life decision making and treatment.

The principle of personal autonomy is central to the bill. The bill establishes a simple, flexible scheme whereby persons can ensure that in the event of their becoming mentally incompetent and requiring medical treatment for any condition, including a terminal illness, their consent or otherwise to specified treatment can be made clear in an advance health directive and/or alternatively treatment decisions can be made by an enduring guardian chosen by them. The bill also clarifies the circumstances in which consent can be given or refused in the absence of an advance health directive, a guardian or an enduring guardian, and clarifies and expands the protection from criminal and civil liability given to health professionals. The bill, however, will not change the position at common law whereby a health professional is under no obligation to provide treatment that is not clinically indicated.

As I outlined, I certainly believe that the bill is very necessary and timely. In terms of this issue in a personal sense, I know that members are particularly concerned about the issue of euthanasia. I am very concerned that any legislation introduced into this Parliament not be viewed as potentially supporting a move towards euthanasia. I certainly do not support that. The government does not support euthanasia, and the bill will not head off in the direction of euthanasia. On that score, I am very happy. In essence - this is a significant point - terminally ill people deserve the right to die with dignity. They need to have their wishes respected. I remind members here today that Pope John Paul II, and many others similarly placed, have been in that situation. This is a position that I believe needs to be retained and, indeed, strengthened.

I believe also that the Acts Amendment (Consent to Medical Treatment) Bill gives certainty to people when end-of-life issues are dealt with. The bill accords medical professionals due protection. Again, as Hon Sally Talbot said, the Australian Medical Association WA branch is generally in favour of the proposed legislation. It also states its opposition to assisted suicide and believes that the bill does not represent a move to euthanasia - something, as I have indicated before, that I hold as an imperative. The AMA's position on the care of severely and terminally ill patients is worth noting. I will quote from an AMA position statement. If the house will indulge me for a second or two, the statement makes the following five particularly relevant points -

- 2.1 The AMA endorses the right of a patient to refuse treatment and the right of a severely and terminally ill patient to have relief of pain and suffering, even when such therapy may shorten that patient's life.

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- 2.2 The AMA recognises the importance of different ethnic and cultural traditions and values at the end of life and emphasises the need for patients to be cared for with respect for this diversity.
- 2.3 Children and adolescents have specialised palliative care needs. Doctors caring for young people should take into account the effects of their illness and death on members of their family and on the broader community.
- 2.4 Doctors should always endeavour to ascertain the patient's views regarding the extent of life-sustaining treatment. Should the patient become incompetent and unable to provide this information, it is appropriate to seek advice from family and friends.
- 2.5 The AMA encourages doctors to listen carefully to their patients and to their families. Doctors should provide accurate information on prognosis and give early consideration to their patients' requests regarding their management. Doctors should seek advice when difficult ethical problems arise.

As members can see, the AMA's position on the care of severely and terminally ill patients is very much worth noting. Geoffrey Dobb, president of the WA branch of the AMA, says that the legislation is very important in resolving uncertainties and respecting the autonomy of patients to consent or refuse procedures or interventions, while, at the same time, potential exposure to medical practitioners under the Criminal Code, especially in relation to pain relief, is addressed, affording professionals new protection. That is something that I believe has been missing from previous legislation.

My support for the bill can be summarised as follows. Firstly, I believe that advance health directives, or the appointment of an enduring guardian, give people a chance to make decisions about their treatment that they might otherwise have been denied. That is very important. I have a bit of an issue with the second matter. In a general sense, advance health directives give people a chance to be fully informed of what will happen to them in the future, and the ability to have some dignity in decision making, although - I will quote from another example a little later - I have some issues on that point, as have a number of other speakers. Thirdly, there have been many times in the past when people have been denied opportunities to make fully informed decisions about their medical treatment because they have become too sick to make those decisions. Finally, I believe that this legislation will be particularly appropriate for people who are in the final stages of AIDS-related illnesses, in which case they can make decisions about continuing with treatment, or about the type of treatment they wish for. It also allows for family members - that is, people involved in loving and caring for that particular person - to be involved in decision making in a formal sense. Previously, there have been cases in which loved ones have been denied involvement in treatment decisions at the expense of other family members who have not been involved in the day-to-day life decisions of that person.

I will now quote from an article about the one issue that I have some trouble with. It is a story in *The West Australian* dated 15 August, written by Father Joseph Parkinson, who, as many members will know, is very much associated with the L.J. Goody Bioethics Centre. The substance of this article is encapsulated in the subtitle in which Father Parkinson says "Freedom of choice in treatment is fine in principle but what if the circumstances change and the patient can't alter their decision". That is a point that a number of people have already made. His article states in part -

It is not the vague shadow of euthanasia that causes me most concern in the Consent to Medical Treatment Bill currently before the Upper House of State Parliament, but the very real prospect of painting myself into a corner.

I have every right to refuse any and all medical treatments I consider to be too burdensome or of little therapeutic benefit to me, and Health Minister Jim McGinty should be congratulated for enshrining this right in statute law.

But unless I am extremely careful, the very same piece of legislation may deprive me of treatments I would actually wish to receive.

Three elements must come together at the time a good medical decision is to be made.

First, I need to know my actual medical condition at the time, and have a fairly clear picture of how this condition will develop and affect me as time goes by.

Father Parkinson goes on -

Second, I need to know what medical treatments are actually available to me at the time, and the benefits and burdens I could expect from each treatment option, including the option to receive only palliative care.

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Third, I need to be clear about what I would prefer to happen, the effects of treatment I would be willing to accept, and direction I wish my life to take as a consequence.

I think those particular words have been articulated in a number of speeches thus far. Another part goes on -

One may well ask whether it is possible for me to have such detailed knowledge at the time I make an advance health directive which may not come into effect until I am rendered unconscious five or 10 years later.

It is certainly true that I can make a truly well-informed, responsible, and ethically sound medical choice only if all three of these elements are in place at the same time.

Obviously I need to be conscious and competent in order to bring all three of these to bear, but the main aim of the Consent to Medical Treatment Bill is to allow me some measure of autonomy even in the event that I am rendered unconscious, incompetent, or otherwise unable to make the decision for myself.

He finishes off his discussion by saying -

But can I truly know now how I might feel in five or 10 years time . . .

I think that sums up the very point that I would like to make. He goes on -

The greatest difficulty I have with the Bill is that advance health directives - or “living wills”, if you prefer - are legally binding on everyone concerned, and could tie the hands of the professionals charged with providing my medical care.

This is the one issue I certainly find most in need of some resolution, and something I would like the minister to perhaps take on board; otherwise, I am happy to support the legislation. I believe, as I have indicated, that it is both timely and necessary in that it rightly reflects the wishes and sentiments of most people in society today.

HON ANTHONY FELS (Agricultural) [9.01 pm]: Never was the saying about the devil being in the detail truer than with this legislation. According to the minister’s second reading speech, he said -

The principle of personal autonomy is central to the bill.

That, of itself, is reason for concern, because in much of contemporary medical ethics the principle of personal autonomy has been elevated to give it primacy over the sometimes conflicting principles of beneficence, non-maleficence, solidarity and justice. It has come to mean “doing as you please” and in so doing has become the catchcry of the pro-euthanasia movement. Classically, the idea of personal autonomy has meant self-determination and, as it applies in the medical field, physical freedom from state invasions into the body. However, if personal autonomy means “doing as you please”, and if all other conflicting principles are to be made subordinate to it, then there remains no logical basis upon which to oppose the legislation on euthanasia. If we were to apply this contemporary definition of personal autonomy consistently, say, in the area of industrial relations, we would have to legalise contracts of employment that afford remuneration below that provided by an industrial award. Indeed, if one were prepared to subordinate principles such as solidarity and justice to autonomy there would be no logical basis for preventing people from exercising their personal autonomy so as to become a slave or a serf, provided they did so of their own accord. Likewise, one could not argue against the voluntary sale of human organs for financial gain if one were prepared to ignore principles such as beneficence and non-maleficence.

The principle of personal autonomy is the cornerstone of liberty, but a good society can never be built on a cornerstone alone. The equally important principles such as beneficence, non-maleficence, solidarity and justice are required to hold liberty in its proper place. This debate would have been better served if the minister, having made mention of one of the key principles of medical ethics, had not placed it on a pedestal and seemingly made all others subordinate to it.

I note the minister’s statement -

According to the Australian Bureau of Statistics, more than 63 000 Western Australians - approximately three per cent of the state’s population - are estimated to be limited in their capacity to make reasoned decisions in their own best interests due to conditions such as dementia, mental illness, intellectual disability and acquired brain injury.

One should add to this number a much larger number of children who, at law, are deemed to lack the competence to make treatment decisions and who also fall under the ambit of this bill.

The most worthy clause of this bill proposes to allow a person to appoint an enduring guardian, or joint enduring guardians, who will have the power to make treatment decisions for the appointer in the event of that person’s incapacity. The bill rightly proposes to limit the power of enduring guardians so as to exclude a range of

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matters, including property and financial matters, consent to adoption and the exercising of a vote in any election. In the absence of both a living will and an enduring guardian, the bill proposes to authorise a third party, to be called a “person responsible”, to exercise the power to make treatment decisions for an incapacitated person. However, there is a serious deficiency in the bill with respect to potential conflicts of interest. In the event that an enduring guardian, or a person responsible, has an interest which conflicts with that person’s moral obligation to make treatment decisions in the best interests of the patient, the bill does not require that that person make those decisions in the best interests of the patient or in accord with best medical practice.

Consider the hypothetical case of a habitual wife beater who attempts to kill his wife by strangulation. He phones the police, claiming he has found his wife lying on the floor unconscious. His wife is rushed to hospital and miraculously lives, but having suffered a loss of blood flow to the brain, is now rendered in a permanently vegetative state. The husband, as the person responsible under the terms of this bill, successfully sues her doctor for failing to diagnose an eating disorder. A court subsequently awards a multimillion dollar payout in damages, sufficient for the husband to provide care to his wife for the rest of her expected life. The husband, who has by now entered into a de facto relationship with another woman, determines that his wife should receive no further treatment, including neither food nor hydration.

Hon Kim Chance: That’s a great plot for a novel. I hope Jeffrey Archer is reading *Hansard*.

Hon ANTHONY FELS: It would be, honourable member, except that it is not too far from the truth in some cases, and it has occurred and there is the capacity for it to occur.

The DEPUTY PRESIDENT: Order, members! I might lose my train of thought if members continue interjecting.

Hon ANTHONY FELS: If, upon the death of that man’s partner, for whom he has an enduring power of attorney, he calculates that he is entitled to inherit the unspent portion of the damages payout, her superannuation, life insurance and other property, it could total a seven-figure sum. Putting aside the initial assault, there is nothing in this bill that would prevent a person responsible, who had a conflict of interest such as in this case, from acting in a prejudicial manner towards the patient in the event that the patient was incompetent.

Hon Sheila Mills interjected.

Hon ANTHONY FELS: The government can bring that one back when the next minister is in trouble, but we will deal with this bill now.

Theoretically, a living will could provide some comfort to this woman if she wished to continue receiving life-sustaining treatment in such circumstances and had clearly expressed such a desire in her living will. Given the experience with living wills elsewhere in the world, which I will address shortly, such comfort is most unlikely.

Alternatively, one might consider an actual case history, such as that of Mrs Terri Schiavo of the United States, to see how this proposed bill would fare in circumstances similar to hers. In February 1990, at the age of 26 years, Terri Schiavo collapsed at home. The official cause of the collapse was determined to be a cardiac arrest induced by a potassium imbalance, which had resulted in oxygen having been cut off to her brain for several minutes. It is worth noting that the cause of Mrs Schiavo’s collapse was disputed, with a neurologist testifying that Mrs Schiavo was admitted to hospital after her collapse with a suspiciously rigid neck, and that he had seen this peculiar constellation of injuries only in a case of attempted strangulation. The report of a total-body bone scan done on Mrs Schiavo when she was in a rehabilitation facility in March 1991 - 13 months after her collapse - described hot spots suggestive of multiple fractures in her ribs, first lumbar vertebrae, several thoracic vertebrae, both sacroiliac joints and both knees and ankles, which were considered to be “presumably traumatic”. Mrs Schiavo underwent rehabilitation for three years following her collapse. Mrs Schiavo’s husband filed a \$20 million malpractice suit against her obstetrician. In November 1992, Mrs Schiavo was awarded \$1 million in damages against her doctor. Just three months later, in February 1993, and after having entered into a relationship with another woman, Mrs Schiavo’s husband had a “do not resuscitate” order posted on Mrs Schiavo’s bed. This was the trigger for 12 years of legal battles that were fought in the courts between Mrs Schiavo’s husband and her family. Without going into detail on all aspects of the case, it is suffice to say that there were bitter disputes about the cause and nature of her illness, the nature of her diagnosis and prognosis, and what her wishes would have been had she been in a position to make her own decisions about treatment. Overhanging proceedings like a dark cloud was the perception that Mr Schiavo, the guardian of Mrs Schiavo, had a conflict of interest.

Common law holds that all competent persons have the right to forgo medical treatment at any time and for any reason. If we are to err at all on the side of caution when dealing with an incompetent person who has not expressed his or her treatment preferences in advance and is relying upon the goodwill of a guardian or responsible person to make potentially life and death decisions on his or her behalf, it should be in favour of a

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presumption that the patient would want to continue to live. I noted earlier that the bill proposes to limit the powers of an enduring guardian in a range of areas, including marriage, adoption, finance and voting. Prudence requires that we further limit those powers so that in the absence of a living will, an order to cease the provision of food and nutrition to an incompetent adult patient cannot be made by a guardian or a responsible person until such time as the patient has entered the terminal phase of a terminal illness.

I wish to address the issue also from the other end of the life continuum. Just as an incompetent adult patient cannot express a preference for a treatment option, especially in the absence of a clearly written and relevant living will, and must therefore be guarded against potential exploitation, we must also consider the welfare of the young, particularly newborn children, who are also dependent upon others for their wellbeing. Under this bill, it would be possible for a responsible person to instruct a medical practitioner to deny medical treatment to a newborn for ailments such as hydrocephaly, which is excess fluid around the brain that can sometimes result in mental retardation. Alternatively, if a baby had Down syndrome and a blocked oesophagus, it would be possible for the responsible person to instruct that the baby not have the minor surgery required to repair the blocked oesophagus so as to bring about the death of the baby. Cases such as this first came to light in the United States in 1982 with what became known as the case of baby Doe. Baby Doe was a newborn boy who was born with Down syndrome and a defect in his oesophagus that needed surgical correction before he could drink from a bottle. Although this operation was routine for newborns, baby Doe's parents refused it and a court upheld their decision. Several parents came forward offering to adopt baby Doe and even to pay for the operation. They were rebuffed and baby Doe died six days after birth without being fed. In 1983, the issue of withholding treatment from newborns with disabilities was again brought to public attention with the case that came to be known as that of baby Jane Doe. In this case, baby Jane Doe was born with spina bifida and hydrocephaly, or excess fluid around the brain. The baby's parents refused to consent to surgery on advice from doctors that, without surgery, the baby would quickly die. In fact, she lived. In 1984, following these cases, the US Congress passed the baby Doe law, which extended the laws defining child abuse to include the withholding of fluids, food and medically indicated treatment from disabled children. Regrettably, Western Australia has not followed the US, even though the 1979 case of Christopher Derkacz gave us reason to do so. As well as incorporating terms similar to those in the baby Doe act, this bill should incorporate the guiding principle of Western Australia's Child Care Services Act 2007, which states in section 6 -

A person or body with functions under this Act must, in the performance of those functions, regard the best interests of children as the paramount consideration.

We must closely circumscribe the withholding of medical treatment from children by a responsible person. We can do no less, especially when section 7 of the draft human rights bill affirms -

Every person has, after he or she is born -

...

(b) the right not to be arbitrarily deprived of life.

Unless we exercise closer scrutiny of this bill, it will for years to come be the source of legal argument and political embarrassment, as courts will apply different interpretations to the words contained within both the legislation and the living wills that lie at its foundation. This has certainly been the experience in other states of Australia and in countries that have introduced living wills. One recent study of living wills in the United States conducted by the Hastings Center, the report of which was tabled by Hon Barbara Scott during her contribution to the debate, concluded that living wills had failed. The report criticises the accumulating paperwork and administrative expense of living wills, and says they deliver paltry or no rewards. The report recommends that patients who are anxious to control future medical decisions should be told about durable powers of attorney, which have many advantages over living wills.

For living wills to work as the Minister for Health envisages, four conditions would need to be met. Firstly, the living wills must be signed; secondly, the makers of living wills must decide what treatment they want and must lucidly write down their preferences; thirdly, the existence of a living will and its contents must be known at the time that treatment is required; and, finally, health professionals must heed the instructions of a living will. I will consider each of those four prerequisites in the light of experience in the United States, where legislation both federally and in most states supports living wills. Living wills have been available in the United States for more than a decade, yet 82 per cent of adults in that country have not signed them. The low level of usage cannot be explained as being the result of a lack of promotion. The US federal government's Patient Self-Determination Act requires that all medical institutions give patients information about their state's living wills, which most states provide for in legislation. Medical and legal journals regularly admonish their professions to ensure that their patients or clients have a living will. University, hospital and numerous other websites promote living wills to patients. A study by J. Holley titled "Factors influencing dialysis patients' completion of advance

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directives” found that only 35 per cent of dialysis patients had a living will. A study conducted in 2000 by C.M. Puchalski, titled “Patients who want their family and physician to make resuscitation decisions for them: Observations from SUPPORT and HELP”, concluded that patients cared less about what decisions were made than that the decisions were made by people whom they trusted, principally their family and their family doctor. Similarly, a further study titled “Why are elderly people not using advance directives” by D.M. High of the University of Kentucky concluded that most intervention participants preferred to defer to family surrogates, and avoided executing advance directives.

If we set aside the fact that 80 per cent of the adult population is unlikely to avail itself of the opportunity to sign a living will, those who do decide to sign a living will will face the daunting prospect of deciding what treatment they want for any particular illness and lucidly writing down their preferences. In determining their preferred treatment well before they begin writing it into their living will, people must be fully informed about their condition, treatment options and prognosis. An article titled “Advance directives: the emerging body of research”, which was written by B. Ott and published in the American Journal of Critical Care, reports that in one study, 201 elderly subjects opted for intervention 12 per cent of the time when it was presented negatively; 18 per cent of the time when intervention was phased, as in an advance directive already in use; and 30 per cent of the time when it was phrased positively. Of the elderly subjects, 77 per cent changed their minds at least once when given the same case scenario but a different description of the intervention. If so many people can change their minds when considering a treatment, varying their response according to whether or not it is presented in either a positive or negative manner, how much more difficult will that decision be when they do not have the benefit of any medical advice? One of the shortcomings of this bill is that there is no requirement to obtain medical advice prior to completing a living will. How can we pretend that the preferences expressed in a living will reflect a person’s informed consent when there is no requirement for him to be informed in the first instance prior to the execution of a living will?

The report by the Hastings Center shows that preferences vary according to the way questions are asked, and whether success and failure rates for various types of treatment and whether long-term or short-term consequences exist are explained first. If we put to one side the question of whether patients are fully informed of their condition, treatment options and prognosis, they still face the daunting task of clearly expressing their preferences in writing. Commonsense reinforces here what innumerable studies have shown, which is that there are too many people who are unable to express themselves clearly in writing. This legislation will help the rich and the elite who can afford a lawyer and may be educated enough to believe that they can make such a decision. The United States response has been - this bill is intent upon duplicating it - to overcome the inability of people to clearly express their preferences on such complex subjects while utilising a “tick a box” format for living wills. A study of the US experience with “tick a box” living wills by Thaddeus Mason Pope titled “The Maladaptation of Miranda to Advance Directives: A Critique of the Implementation of the Patient Self-Determination Act” concluded that living wills baffle patients. Living wills fail because their authors are struggling to work out exactly what treatment they want in a particular circumstance. It is a task that is complicated over time as treatments vary and improve. People have to imagine all the circumstances in which it might apply and to clearly express their preferences.

Putting the above side, what good is a living will when an urgent decision about treatment is required? Let us imagine a pedestrian being hit by a car and a paramedic is on site, but the person’s identity is not known at the time and it is also unknown whether he has signed a living will that clearly expresses his treatment preferences. In such a case, can the estate of the deceased person successfully sue an emergency specialist or medical staff who treated the patient? The report of the Hastings Center mentions a study in the US that found that of 182 patients whose charts were reviewed and who had signed a living will, only 26 per cent of the charts accurately recorded information about the living wills and only 16 per cent of the charts contained a copy of a patient’s living will. Fortunately, this bill recognises this limitation of living wills and has provided a solution in proposed section 110ZI(2) whereby a health professional is granted authority to treat a patient who needs urgent treatment in circumstances when the patient suffers legal incapacity and it is indeterminate whether a living will exists and it is not practicable to obtain a treatment decision from a guardian. Although the bill overcomes this particular limitation of a living will, it reinforces the case that their practical use is, at best, problematic.

Living wills are not self-executing. Living wills must be interpreted so as to determine whether the precise medical situation described in it has arisen and to determine what treatment preference the living will commands. The experience of other jurisdictions give rise to great concerns. We should take the case of Holland, which has legalised voluntary euthanasia. A report on the Dutch experience with voluntary euthanasia published in the prestigious British medical journal *The Lancet* documented 1 030 cases in which patients were euthanased without an explicit request, let alone consent. If doctors can act as a law unto themselves on so serious a matter, the chances that they may do so with treatments of lesser consequences can only be greater. One might finally consider whether there is any evidence from international experience that suggests that living wills might help in

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some way in determining the treatment preferences of patients. A US study by L. Emanuel titled “The Health Care Directive: Learning How to Draft Advance Care Documents” published in the *Journal of the American Geriatrics Society* reported the results of a randomised trial in which researchers asked elderly patients to complete a living will. A second control group of elderly patients did not complete a living will. Without any prior consultation, members of the elderly persons’ families were asked to predict the patients’ treatment preferences. Those unable to consult a living will predicted preferences 70 per cent of the time. Those family members who had the benefit of consulting the living will did no better in predicting treatment preferences than the first group who were denied access to the living will.

The international experience is overwhelming. Living wills have been a failure. Living wills have only added complexity and administrative expense to the US health and legal systems. Patients anxious to control future medical treatments should make use of the enduring power of guardianship.

I now turn to the area in the bill that provides for euthanasia by omission. I will preface my remarks by restating that I do not believe life-sustaining treatments are obligatory when they are therapeutically futile or when they impose an undue burden on a patient. As I have already made mention, under this bill there is no requirement for a guardian or person responsible to act in the best interests of a patient, nor to make treatment decisions in accordance with best medical practice. The clause of this bill that causes my greatest concern about the potential for euthanasia by omission is proposed sections 110ZK (2) and (3). In essence, the proposed sections state that if a health professional takes treatment action, which is defined as the decision to commence or continue a treatment or to not commence or to discontinue a treatment, reasonably assuming that some other health professional has ascertained that the treatment action is in accordance with the treatment decision, the health professional is, for all purposes, to take the treatment action in accordance with the treatment decision. That is, if a doctor of his own accord decides to suspend the provision of food and/or hydration or place a sign on the bed of a patient stating that there should be no resuscitation, no external cardiac massage or no intubation, he would be acting legally provided he had some basis to reasonably assume that some other health professional has ascertained that the treatment action is in accordance with the treatment decision.

Proposed subsection (3) states that the validity of the treatment action undertaken in proposed subsection (2) applies even if -

- (a) the patient is in fact able to make reasonable judgments in respect of the treatment action; or
- . . .
- (e) the circumstances in which the treatment decision in the advance health directive or the guardianship order or enduring power of guardianship may be acted on in fact do not exist or have not arisen; or
- (f) the advance health directive, guardianship order or enduring power of guardianship in fact does not authorise the making of the treatment decision; . . .

A practical test of the proposed section would be to judge it against the case of baby Christopher Derkacz, to which I have already briefly referred. The 1979 case of baby Christopher Derkacz involved a baby with Down syndrome who, at the time of its admission to hospital, was suffering from croup, which is a common respiratory illness amongst children that involves inflammation of the upper airway that causes a rasping cough. Baby Christopher Derkacz died after being admitted to hospital for treatment and as a result of the medical consultant concerned instructing the hospital registrar to place on his chart instructions that he was not to be resuscitated or given cardiac massage. The coroner was unable to conclude his inquiry into the case as several vital witnesses, including doctors and nurses, refused to give evidence. The coroner is on record as stating that the hospital records contain an alarming note that the baby should receive no resuscitation, no external cardiac massage and no incubation. Under this bill the registrar concerned could use proposed section 110ZK as his defence, arguing that he relied in good faith on the instructions of the consulting doctor. In turn the consulting doctor could use proposed section 110ZK as his defence claiming that he acted in good faith on what he understood to be a treatment decision by the foster mother. After all, if a person is prepared to kill a baby by denying him treatment, what will stop him from lying to a coroner? Effectively, the proposed section removes all criminal responsibility from a doctor who ignores the instructions of a living will or a guardian and who, of his own accord, chooses to deny treatment or to withdraw treatment from a patient for any reason.

I believe that this bill needs more than a few cosmetic amendments. I oppose the bill in its present form.

THE DEPUTY PRESIDENT (Hon Ken Travers): Before giving Hon Bruce Donaldson the call, I add to the comments made by the chair earlier. I remind members to acquaint themselves with standing orders 78 and 79 and encourage them to acquaint themselves also with standing order 83. I advise the house that the reading of a speech is in breach of the standing orders. Members can use copious notes but the reading of a speech verbatim, unless it is for a direct quote, is in contravention of the standing orders.

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HON BRUCE DONALDSON (Agricultural) [9.29 pm]: I will not speak for long but I will make a few comments about this bill. We can look at what is reality, what is theory and what is practised today and has been practised for some time. We talk about people making provisions for their future and for the future of their families. However, a number of people do not even make a will and many people who do make a will forget to update it. That causes huge headaches and problems at a later stage for the trustees of the will or for the Public Trustee. Let us imagine a graph of people aged between 18 and 80. The people at the bottom of the graph who are 18, 20 or 25 think that they are bullet proof and people who are married at 30, 35, 40 or 45 do not think about death.

Hon Robyn McSweeney: I'm not.

Hon BRUCE DONALDSON: The member is placed at the top of the graph!

I do not believe that many people will take up the offer of making an advance health directive. If people are lucky enough to have a family and the family is together, what happens around the kitchen table when they talk about their life expectations is what matters. I have a son who, when he was 23 years old, was the passenger of a vehicle that was involved in a traffic accident in Perth. Luckily, it happened close to Sir Charles Gairdner Hospital. He was given only a two per cent chance of surviving. The doctors operated on him and took off half his skull. When my wife and I arrived at Sir Charles Gairdner Hospital from the farm, the first thing the registrar from Sir Charles Gairdner Hospital asked us was what our view was on a patient's quality of life etc. We said that we would never forgive the hospital if our son became a vegetable or would never walk again or whatever and that our son would not forgive the hospital either, because we had discussed these matters together as a family. The registrar said that the hospital would take that into consideration. That is fine. Do not worry; I support the principle of the bill. If this bill will protect the health professionals, I fully support it. By the Monday night the pressure in my son's brain had built up again. We were in the intensive care unit where there were patients in some of the other beds. The registrar and four doctors were standing not far behind us. I thought that they were talking about the patient in the bed next to my son, but they were talking about my son. They were discussing whether to turn off the life support machine. They decided that night that they would not do it. It was not possible for the surgeons to take out the other half of my son's skull, and so it was a matter of whether the pressure on his brain would keep increasing. The pressure in his brain subsided overnight. They had made the right decision and my son got a lot better. The specialist who operated on him was Dr George Wong. He said that he never thought my son would be in the situation that he is in today. That is just one of those things that happen in life.

I am sure that all members have seen family members or extended family members in hospital and have wished to goodness that the doctors would increase the level of morphine that was administered through the pump. At the end of the day, it is not the patient who suffers; it is the family. By that stage, the patient is either in a semi-comatose state or whatever. For 10 days my father-in-law was given no hydration or food whatsoever but his heart was so strong that it would not give out. However, his chance of having an adequate quality of life after suffering a serious stroke was nil. The doctors at that hospital made a decision, but they asked the family what we wanted to do. I know that my father-in-law did not want to be kept alive by a life support system that can keep a person going forever. My mother made the same choice. She told her doctor, the minister of the Church of England and each family member to not resuscitate her if she drifted off into a coma. She told us that she wanted to go. The doctors made that decision, but they asked us first. I would hate to think that litigation would be brought against any medical professional on such a matter because they do not make that type of decision idly or lightly. I have great faith in the medical professionals who make that type of assessment.

I have considered the position of organ donors. We all encourage people to become organ donors and we have all registered to become organ donors, although my organs are probably no good to anybody because I am too old now! An organ donor can suddenly die in a car accident or whatever when the person is very young. However, the family of the deceased can step in and prevent the person's organs from being donated, which I think is wrong. It is a reward in itself to see the benefits that other people have received from organ donations. Gee whiz, a family member can stop it. I am worried about the extent of the so-called living will. How does it stack up? It says in the second reading speech and in the bill that there is an order of priority. Many people do not make a will for the distribution of their assets to their family, or they do not update it. Therefore, I believe that only a minimum number of people will make an advance health care directive. How can people make that choice when they are 35? I know that it can be reviewed in 10 years when the person is 45 or whatever, but it is probably one of those things that they would never get around to doing. I would prefer to rely on my own family. My brother and sister know exactly what I want to happen if something happens to me. The medical professionals would ask my wife and family what their views were if they considered that I would have no quality of life and the medical professionals would make the final decision. They have always made it very clear that it is their decision to make, but they do seek the advice of the family.

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It seems to me that this bill, which was a fairly simple piece of legislation, has become very convoluted. Maybe too many i's have been dotted and too many t's have been crossed. I do not know. I may be wrong. It might need to be that way for legal purposes. I wholeheartedly support the protection of the medical profession. They are in a position to make the final decision on what happens to a person. The medical professionals in hospitals and in nursing homes make those types of decisions 24 hours a day, seven days a week, 52 weeks a year. Regardless of whether a person writes a living will, circumstances can change. I support protecting the health professionals and I support the forward-thinking people who will make an advance care directive to provide that they do not want to be resuscitated. That is fine.

We could look at someone who has dementia, whose health has gone backwards rapidly and who has lost weight suddenly. A friend of mine recently died from cancer. He was 60 years of age, and he died at home. He did not want to be put on a life support system. That is why he went home. The medical professionals made sure that he had a morphine pump, and they were able to manage his pain level. As the pain level lifted, they increased the morphine. Members know the end result. That saved him from that sort of pain. At the end of the day, when people have dementia they are lying in bed; they have not made a living will; they are incapable of doing so; and their family has not been told what they want before they get to that stage. It is up to the health professionals to make those decisions. It is very hard on the family. The family want to visit but they are very distressed when they leave.

I support the bill. I have heard what some of my colleagues have said. I do not know whether anybody will suggest that the bill be sent to a committee. I do not know whether it will be referred to a committee. I say to the minister that it is a great bill in theory, but in practice, like all the legislation we have passed, people will forget about it within the next five years. Probably 14 statutes have been passed over the 14 years that I have been here, and I could not name half of those bills. We pass 83 or 84 bills a year. How many people in this chamber remember some of the bills passed five years ago? Unless one happened to be a minister or an opposition spokesperson who had carriage of a particular piece of legislation, we all forget. It is impossible to remember. At the end of the day, if the legislation is needed, let us protect the health professionals. I have indicated that to a number of my friends who are in that profession. They may be frightened of having litigation against them for making a decision that they considered very seriously. They do take an oath to save lives. There could be a very good reason for moving from that oath; that is, to assist those people. I absolutely support the principle of the bill.

HON KATE DOUST (South Metropolitan - Parliamentary Secretary) [9.43 pm]: I too want to put on record that I support the principle behind this legislation. It is very important that we as individuals have the capacity to make decisions about the manner of treatment that we are provided with at the end of our life. When this legislation was first proposed - I think a discussion paper was put out a couple of years ago - I genuinely believed that that would be the main focus of the legislation. It was to be along the lines of what was known as the Taylor bill, the Medical Care of the Dying Bill, that was debated in an earlier parliament. I felt quite comfortable with that legislation. I thought that if that is what we would be dealing with, it would not cause me any great dilemma.

When I first went to a briefing before the bill was introduced, a number of people from the medical area and from the bioethics area attended. Dr Bridges, Scott Blackmore and Father Walter Black from the L.J. Goody Bioethics Centre spoke about the issues and the benefits that they saw in this legislation. I fully support the work that they do. We have a very good system of palliative care in this state. I have always believed that it is something that we need to put more dollars into and expand the capacity for palliative care. I listened eagerly to what those gentlemen said to us. I took away from the meeting the view that the bill was more about providing assistance and relief to people working in that area so they did not have to deal with any legal dilemmas for people in their care. Their role is very different from that of doctors operating in some of our hospitals because primarily their focus is on providing comfort and care in the last days of a person's life. Sometimes the decisions that are made may not necessarily be decisions that we understand, but they are made for the right reason for that individual. I felt very comfortable with that.

I sat down with the advisers to go through the detail of the bill. Having listened to those doctors, I thought it would be pretty straightforward. I raised a number of questions to which I could not get the answers that I wanted. In fact, the briefing threw up more questions for me than I anticipated. I sought advice from a number of people outside Parliament - ethicists and a number of lawyers - to go through the bill for me to clear up some of these questions because I was not getting the answers I wanted. Like other members, a number of people have contacted my office who are very supportive of this legislation. A number of other people have contacted me who, through their own work or life experience, have set out some quite specific concerns about aspects of the bill. I suppose that is where I have come to. Whilst I support the principle of the legislation, I know that as an individual, I like to have control over every aspect of my life where I can, and I would hopefully like to have

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control over how my death occurs as well. I know that that is not possible in every case but if I am lucky enough to live to an old age, hopefully things will be fairly smooth. Sadly, that is not the case for everyone.

Hon Simon O'Brien: You've got a long way to go.

Hon KATE DOUST: I certainly hope so.

I want to take members through pieces of correspondence I received from a palliative care doctor who set out some very reasonable concerns about this bill based on her work experience in the industry. I also want to take members through some very specific concerns about the bill that I hope the minister will be able to provide some response to once we have concluded this part of the debate.

I will go through some general issues before I get to the specific ones. Whilst this bill mainly refers to living wills and enables people to set down in black and white how they would like to be treated at the end of their life, as other members have alluded to, this bill is not simply about end-of-life matters. It can be picked up at any point in life. I was trying to think of other examples. The article that Hon Matt Benson referred to by Father Joe Parkinson in *The West Australian* last week gave the example of a pregnant woman. Would we encourage pregnant women to write an advance health directive in case of certain events occurring during pregnancy or delivery? Sometimes things happen during our lives that make us stop and think about our own health situation. Is that the point at which we would make an advance health directive? I picked up on Hon Bruce Donaldson's point that when one is very young, one thinks one is invincible. One of the issues I was going to raise with the minister is that if this bill goes through, whether in this format or in an amended format, how would we encourage people to engage in advance health directives? A number of people have spoken about a range of different formats that exist around the world. I am interested to see what type of format the government is proposing for this type of directive in WA. I always take the view that these things need to be kept fairly straightforward and simple. I appreciate that this area is very complex, because how can people predict, at any point in their lives, what health matters will befall them, or what changing technologies or medicines will be in place to deal with those health matters? Will some sort of formatted advance health directive be set out in regulations so that people can use a template or some sort of model, or will we just rely on people drafting their own directives and presenting them to lawyers?

I also pick up on a point made by a couple of members about people seeking advice before signing off on these directives. We seek advice on many other decisions we make in our lives, whether they be about purchasing a car, buying a house or engaging in academic study. We talk to people about how we should go about those things. A bank will send people buying houses to get financial advice to see whether they are eligible for finance, or if they can afford the repayments. People have talked about getting advice on advance health directives. It is important that an amendment be made to this bill to provide that a directive cannot be signed off unless a medical practitioner with knowledge of the person's health situation can provide advice. In connection with that, I raised with the advisers some months ago the matter of the broad definition in another act of a "health professional" who might be able to give advice. I think that definition even extended to Chinese herbalists, acupuncturists and a range of other people. It is very important that if people are going to put their minds to the question of their treatment at the end of their lives, they have appropriate advice, preferably from somebody who has dealt with them in that capacity. If this bill is generally about end-of-life issues, we need to tighten it so that it reflects that, rather than it remaining so broad.

I am also concerned about the time frame for review of an advance health directive. Other members have said that 10 years is too long; it should be five years or less. As in a lot of areas, we change our minds and our perceptions about how things occur as we get older. Our personal situation and our family environment change over time, and those things need to be taken into account.

There is no mention in this legislation of the best interest. I think this has been raised by other members. I know that Hon Bruce Donaldson talked about the family making those decisions for people, but I think there needs to be a definition in the legislation about what constitutes the best interests of the individual patient, either from the medical practitioner's viewpoint or from the viewpoint of an enduring guardian appointed to represent the patient. Both should be making decisions in the best interests of that person. From talking to some people, I know that it is sometimes difficult to provide an adequate definition of "best interests", but I hope that the government will give consideration to this, because it may clarify for a number of us how some situations could be managed, and allay some of the concerns.

I do not have great difficulty with the way the hierarchy of responsibility is currently structured, because I know the minister slightly altered the definitions of "spouse" and "partner". My only concern is what would happen in the event of a breakdown in the relationship of the person who is deemed to be responsible at that layer of the hierarchy and in the event that decisions need to be made at an important point. How will that be dealt with? Let us face it - families, even in the best of circumstances, can have fallings out from time to time. Often such things

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can happen at the worst of times, when such decisions need to be made. I have a concern about how that is to be dealt with.

I have other concerns about the involvement of the State Administrative Tribunal, and not just with the time taken for cases to get to hearings and determinations. I think it becomes very legal; I have worries about a total stranger stepping in and being able to make decisions regarding somebody about whom he has no knowledge. I do not believe that these types of directives should be binding; they should be advisory. That would give everyone a bit of flexibility about how things should be dealt with. The issue has been raised with me about some medical staff working in Catholic hospitals who do not have the option of conscientious objection under this legislation. Without that option, such people could be compelled to make decisions or perform tasks that go against their private views. That issue needs to be dealt with for that sector of the community, because it will create dilemmas for them, depending on what an individual specifies in a directive.

Those are some general concerns I wanted to raise. I sought advice on some specific concerns, and I will go through some clauses of the bill on which I hope the minister will provide some information. Although I support the principle behind this legislation - it is very important that we give personal direction to the medical staff and to our families about how we want to be cared for or what sort of treatment we wish to have - I am not too sure about how I will deal with this bill. If some of the matters I have raised and that I have heard other people raise cannot be resolved, I might have to vote against this bill. That is not to say that I do not support living wills legislation at all; it is just that I may not necessarily agree with the way this bill has been drafted. I will go through some of the clauses of the bill about which I have concerns, and upon which I have sought advice. In clause 11, proposed section 110B of the Guardianship and Administration Act 1990 states -

A person who has reached 18 years of age and has full legal capacity may make an enduring power of guardianship . . .

How can anyone be sure that that was the case when the enduring power of guardianship was made? Proposed section 110E provides that an enduring power of guardianship is not valid unless it is prepared in the correct way. Who will check that out, especially in an urgent situation? This comes back to another issue. If a person makes an advance health directive and chooses to register it, and staff are made aware of what is in that directive, that is all well and good, but if a person does not choose to register the directive, and is in an emergency situation, how do the staff know what the directive is, and how do they know that it met all the relevant criteria when it was signed? Proposed section 110G provides that an enduring power of guardianship may limit the functions of the enduring guardian, the circumstances in which the enduring guardian may act or include directions about how the enduring guardian is to perform any functions. Again, who will check the original instrument to ensure that the enduring guardian is acting within the power he has been given? I refer to proposed section 110I, "Priority of enduring power of guardianship". The enduring power of guardianship is subordinated to an advance health directive, if one exists. Who will check whether an advance health directive exists before complying with the directive of the enduring guardian? Proposed section 110Q provides that an advance health directive is not valid unless made in the correct way. The bill stipulates the manner in which it should be set out.

Debate interrupted, pursuant to standing orders.