# HOUSE OF ASSEMBLY

## WEDNESDAY 14TH NOVEMEBER 2012

## ADVANCE CARE DIRECTIVES BILL

Adjourned debate on second reading.

(Continued from 13 November 2012.)

**Mr PEDERICK (Hammond) (12:34 ):** I rise to speak on the Advance Care Directives Bill 2012, which was tabled by the Minister for Health in this place on 17 October 2012. This bill is about enabling competent adults to make decisions and give directions in relation to their future health care, accommodation arrangements and personal affairs, and to appoint substitute decision-makers to make such decisions on their behalf. Back in 2007, the government launched the Advance Directives Review with the release of an issues paper looking for public comment.

An independent Advance Directives Review Committee was established, with the former health minister, the Hon. Martyn Evans, as the chair. The 11-member review committee was supported by a panel of experts across a broad range of areas. Over 120 submissions were received on the issues paper from health, aged-care and community care professionals; lawyers; community organisations; consumers; Aboriginal communities; government agencies; and financial institutions.

After 18 months of deliberations, this committee reported to the Attorney-General in two stages, with 67 recommendations. In 2011, the Australian Health Ministers' Advisory Council endorsed the National Framework for Advance Care Directives. The framework provides a lexicon of terms to facilitate national harmonisation, a code for ethical practice, and best practice guidelines. The bill, in my understanding, substantially accords with the national framework and only rejects one recommendation of the review, namely, that the integrated directive encompass powers of attorney.

The bill consolidates three different advance directives that are currently available. These include the medical power of attorney, which comes under the Consent to Medical Treatment and Palliative Care Act 1995. The scope of this is that the medical agent is limited to making medical decisions of behalf of the person. The model involves an agent to act in the best interests of the subject, with the capacity for directions. It applies when the grantor is incapable of making decisions on his or her own behalf. The decision of a medical agent can only be reviewed by the Supreme Court.

Anticipatory direction comes under the Consent to Medical Treatment and Palliative Care Act 1995. People need to list conditions and specific treatments they want, often in advance of illness or condition. The model is based on a precommitment to specific decisions; that is, a person cannot appoint a substitute decision-maker. This only applies when a person is in the terminal phase of a terminal illness or a persistent vegetative state. There is no dispute resolution process.

The third advanced directive that is currently available is the enduring power of guardianship, which comes under the Guardianship and Administration Act 1993. Its scope is that, except where there is a medical agent available and willing, an appointee can make medical and dental treatment decisions on behalf of the person, otherwise 'the powers at law or in equity of a guardian'. The model is to act in the best interests of the subject, and it applies when the grantor becomes mentally incapacitated. If there is a dispute or disagreement in relation to the enduring power of guardianship, the Guardianship Board can hear and decide the matter.

These instruments require different forms to be completed and have different witnessing provisions. The bill will bring all these directives to one form and be governed by one act. Financial powers of attorney and wills are not affected. The bill is founded on the principle of supported decision-making, that people should be supported to make their own decisions (lower-level decisions) for as long as they can. From what we have been informed, the directives will apply in any period of impaired decision-making capacity, whether temporary, fluctuating or permanent, as directed by the person in their advance care directive in various periods of life. For example, not just at the end of life, unconscious, degenerative conditions.

Assessment of capacity will now be decision-specific, not global, and made when the decision is required. The scope of the directive is that, while enduring powers of guardianship is currently as broad as the powers of the guardian at law, medical power or attorney and advance directions are focused on medical issues. The new advance care directives are broad, including residential accommodation and other personal matters.

The bill aims to make it easier for people to express their views and preferences and to have confidence that they will be known and respected in the future. The type of information people will be able to include in the new advance care directives is significantly expanded, and you can include issues such as: the values and goals in life and care; what is important to you when decisions are being made for you by others; instructions relating to various periods of life, for example not just at the end of life; what levels of functioning would be intolerable; and where and how you wish to be cared for when you are unable to care for yourself.

The bill does not prevent people specifying health care they do not wish to receive, including refusals of life-sustaining measures, such as CPR, artificial hydration,

nutrition or ventilation and the circumstances under which such refusals would apply. Instructions and expressed preferences, other than refusals of health care, must guide decision-making, but are not binding on others.

The bill has been put to enable as much flexibility as possible for the people completing these directives and there are different options. You can use written instructions and that can include preferences and wishes and the appointment of one or more suitable decision-makers. Secondly, you can have only written instructions and preferences; and the third point is the appointment of one or more suitable decision-makers without written preferences.

Subject to any contrary provisions contained in an advance care directive, an appointed substitute decision-maker can make all the health care, accommodation and personal decisions the person could lawfully make if they had decision-making capacity, and the decision has the same legal effect as if it were a decision of the person themselves.

The bill requires that substitute decision-makers must make decisions using the substituted judgement decision-making standard to make the decision they believe the person would have made in the current circumstances if they had access to the same information.

Both the witness to the form and the substitute decision-maker are subject to conflict of interest disqualifications. Throughout the process there is a new dispute resolution process, and there are forms and different ways the advance care directive must be put; it must be completed using a form approved by the minister. I also note that currently, South Australia is one of the only jurisdictions where advance care directives completed in other jurisdictions are not recognised, and this bill takes note of that.

The bill also amends the Consent to Medical Treatment and Palliative Care Act to clarify consent arrangements in the absence of an advance care directive for patients unable to consent and introduces a dispute resolution process, including voluntary mediation.

Currently, the Guardianship Act specifies that, where there is no legally appointed representative such as a guardian, enduring guardian or medical agent, and limited relatives can consent to health care on behalf of an adult with a mental incapacity.

Amendments to the consent act lay down the 'responsible person' who can consent to healthcare on behalf of a patient with impaired decision-making capacity if there is no advance care directive. The person is to be identified by the following hierarchy, and they run in order:

1.A guardian appointed by the Guardianship Board, provided that the guardian's powers do not exclude making health care decisions.

2.If there is no guardian appointed, a prescribed relative of the patient can consent without a hierarchy related to whether the person has a close and continuing relationship with the patient.

3.If there is no guardian or prescribed relative, an adult friend.

4.If there is no one who meets the previously mentioned categories of persons responsible, an adult charged with overseeing the ongoing day to day supervision, care and well-being of the patient who is available and willing can make a decision.

5.If there is no-one who meets the above criteria who is available and willing to make a decision, upon application, the Guardianship Board can consent to the proposed treatment.

So, there are quite a range of people and it is quite a lengthy list. I wonder whether it is too long, but perhaps that is what is needed. There has obviously been consultation. The responsible person will be subject to a similar dispute resolution process to that for advanced care directives.

I have had some correspondence with regard to this bill from a lawyer who works in this field of health care and advanced care directives. He is a person with an interest in the Respecting Patient Choices program. He is quite a proponent of advanced care directives and says that everyone should have them, but he has certainly raised a few concerns with me that the minister needs to address before I am able to support this piece of legislation. His concerns are:

(1) That some people may die needlessly and unintentionally if they sign Advance Care Directives in the form proposed;

(2) Pursuant to S.11 of the Bill the person making the Advance Care Directive needs to understand the consequences of giving an Advance Care Directive rather than the consequences of the decisions they have (using the current Anticipatory Direction, Medical Power of Attorney and Enduring Power of Guardianship forms);

(3) Pursuant to Ss.19 & 36 of the Bill an Advance Care Directive refusing life sustaining measures (eg CPR) can apply to any period of incapacity in the circumstances specified rather than to the terminal phase of life, as is the case presently;

(4) Pursuant to S.36 of the Bill health care refusals are binding on all health practitioners, even in emergency events, rather than that responsibility resting with

the medical practitioner(s) or those under their supervision in such circumstances. Health practitioners who do not comply with the Advance Care Directive could be charged with assault and battery and also cited for professional misconduct;

(5) Pursuant to S.5 of the Bill any subsequent health issues arising from the condition, to which the Advance Care Directive refusal relates, cannot be treated;

(6) Pursuant to S.37 of the Bill a health practitioner, who has an objection to facilitating an Advance Care Directive treatment refusal, has to refer the case and patient on to someone who will comply with the Advance Care Directive, even if the consequence of doing so results in the needless and unintentional death of that patient;

(7) S . 23(4) of the Bill infers that an express directive could refuse the natural provision of food, fluids or palliation rather than inferring the opposite.

He also notes that health practitioners who discussed the implications of this bill in the last week or so have put forward the following suggestions regarding the bill in its current form:

(1) That S.19(1) of the Bill be amended to state that 'an Advance Care Directive containing a refusal of life sustaining measures (whether expressed or implied) will, for the purposes of the Act, be taken to be a binding provision when the person is in the terminal phase of a terminal illness or condition'—thus having the same meaning as set out in the current Consent Act, although terminal condition could include 'ag e ing';

(2) That in S.11(5), a subsection be added to the Bill to note that the person's refusal of life sustaining measures, when that person is not in the terminal phase of a terminal illness or condition, will be less open to enquiry as to its validity if the Advance Care Directive indicates that the person has been medically informed of the consequences of such refusal of life sustaining measures;

(3) That a provision be added to S.23(1)(a) of the Bill to the effect that any decision(s) made by the substitute decision maker regarding life sustaining measures are binding when a person is in the terminal phase of a terminal illness or condition;

(4) That the provision that any subsequent health issues , arising from the condition, to which the Advance Care Directive refusal relates, cannot be treated be deleted from S.5 of the B ill;

(5) That if S.5 of the Bill is removed then S.37 of the Bill could be removed because there would be no cause for conscientious objection, in that a person could be allowed to die naturally in the terminal phase of a terminal illness or condition, that

fits with codes of professional practice and ethics to which health practitioners currently adhere; and

(6) That, with respect to S .23(4) of the Bill the current version of the Consent Act be left intact and so remove the words ' unless there is an express direction to the contrary' from this Section of the Bill.

My legal friend indicates that he is concerned and, as I have just indicated to the house, he wants these points debated so that all possible unintentional consequences of the bill that have been detected by the health professionals can be avoided.

I note that my lawyer friend is very supportive of advance directives, but he wants them in the appropriate form, and I could not agree with him more. I think they are probably a very useful item for people's care and their proposed needs when they have the capacity to make those decisions, when they are of sound and competent mind, but the issue is: when do the advance care directives take place?

My reading of these comments and my reading of the bill indicate that it could be at any stage of your life and not just with a terminal illness, so I need the minister to outline to me that it will not apply to a younger person who might have an accident on a farm or a car accident and someone checks out the advance care directive that they want to withhold treatment and that person will be let go. I do have a real concern with that. I think there needs to be clarity and, if I am given that clarity, I will be able to support the bill, but I am just concerned that there are quite a few loose ends that need to be tied up.

I think it is a good idea to bring these three forms of advance care directive into the one form so that people can give their anticipatory direction, but we just need to make sure that people are not left unwillingly to die, quite frankly, if that was not the point they were trying to make. We want to make sure that these directives are for the very appropriate end-of-life time when they may be needed and not in a situation where persons could be resuscitated and perhaps go on to live an extra 20, 30, 40 or however many years and have a productive life.

I have mentioned before in this house my opposition to euthanasia. I am told that this bill does not directly involve active euthanasia, but I want to be satisfied in my mind that, if this becomes an act, the right safeguards are in place to protect the citizens of this state. I commend the idea to bring the three directives together and that there will be interstate recognition of the advance care directive from South Australia.

Debate adjourned on motion of Dr McFetridge.