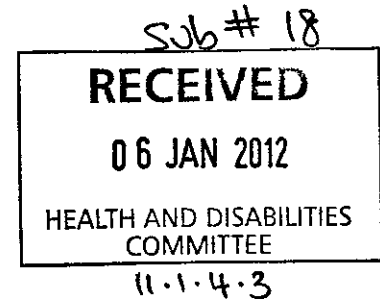


Submission to

**Queensland Government Health and Disabilities Committee (HDC)**

Inquiry into the Queensland Law Reform Commission's (QLRC) recommendations that are within the committee's terms of reference, the current laws as they relate to guardianship and other issues on which the committee seeks comment

From



Brisbane

January 6<sup>th</sup> 2012

Dear Research Director

I thank the Committee for the opportunity to submit comments at a late stage to this inquiry on the important issue of ethical, legal and clinical guardianship of people incapable of self-representation. I see this as an issue of critical importance in the twenty-first century, especially in a society that has become increasingly secular, technologised and individualistic.

Many of the difficult questions that arise relating in particular to end-of-life care and the care of those who cannot speak for themselves who may not be an in end-of-life scenario arise because of the very long-standing and inextricable mélange of social, ethical, religious and medical traditions that exist in Western developed countries. Nevertheless, attitudes do change and it behoves the government of a civilised nation to do its best to accommodate the enduring and/or last wishes of such people of whatever ethnic, religious or ethical background.

It is not compulsory that a citizen should take out an Advance Health Directive or appoint an attorney for health matters. Whilst it can be argued that there are many reasons why it is desirable to do so, it remains a matter of choice and should continue to remain so but for those who do indicate their wishes in certain medical circumstances, there should be very tight safeguards in place so that these wishes can be respected.

It is heartening to see the government attending to these issues by initiating this Inquiry. The National Policy Framework must be seen as a positive step forward. Welcome too are the GAA Act and the POA Act that provide the legislative framework for decision making for adults whose capacity is impaired.

I make this submission within the following parameters:

1. As a single, educated, middle class woman aged 64 yrs of no religious affiliation who lives alone.
2. As a person who has no parents, siblings, children or other relatives.
3. As a person who is concerned about the right of people, who so choose, to die with dignity and with as little suffering as possible without breaking the law.
4. As a person who has taken out an Advance Health Directive (AHD) and who has instructed my enduring power of attorney for health matters that I want my AHD respected in every way.
5. As a person who has studied the Issues Paper pertinent to this Inquiry.

I am especially concerned about how people living alone, particularly the elderly, can make the existence of an AHD known to paramedics and health providers should they unexpectedly be taken into hospital or other care situation with impaired cognitive function, even if only temporarily impaired. There may be scenarios in which such a person would receive immediate treatment (or even ongoing but temporary treatment until full cognitive function returned) that they would otherwise not wish to have.

I thank the Committee for its consideration of my submission.

## Specific comments on the Issues Paper

### Section 2.2.3

*Should the POA Act be amended to clearly state that an advance health directive can not operate if the directive is uncertain or if circumstances have changed to the extent that, had the patient known of the changed circumstances they would think the advance health directive was inappropriate?*

- 'uncertain' by whose definition? A relative? An appointed attorney for health matters? A nurse? A doctor? All four? For this to be feasibly implemented, the word requires either a) definition or b) limitation as to whose opinion is valid regarding the alleged uncertainty.
- Similarly, the patient thinking that the health directive was inappropriate in changed circumstances is something that a third party would have to be very sure of if not able to prove beyond doubt that this would have been the case. This would need to be an individual with intimate knowledge of the patient. **Risks remain.** Such an individual eg. a husband, may indicate that his wife would change her mind about the AHD in the changed circumstances yet the provision of treatment may still, in certain scenarios, result in an **unexpected outcome** that his wife may have deemed unacceptable eg. be institutionalized; be fully paralysed; be in a vegetative state. Such an alleged 'change of mind' may also be influenced by the age of the patient. A 25 year old may well reconsider the validity of an AHD whereas a 95 year old individual may not.

### Section 2.3.1- 2.3.3

### QLRC recommendation 9.11

*Would the proposed obligation on health and disability services improve health providers' access to and awareness of advance health directives and enduring powers of attorney?*

*What impact would the proposal have on hospitals, residential aged care and residential disability facilities and health providers?*

- I would agree that an obligation as is outlined in this Paper would seem an essential first step in enabling appropriate care and treatment of an admitted patient and thus improve the care provided. This seems to be particularly so in the case of a patient with impaired cognitive function.
- I would also think it imperative that where an AHD exists, a copy should form part and parcel of ready to hand medical information about the patient and be either in the hands of the treating medical team or the facility management.
- When a person is admitted to hospital, a residential aged care, residential disability facility or palliative care hospice with impaired cognition, it seems logical that the first port of call to obtain knowledge of the existence of an AHD would be either a) a family member or b) the patient's doctor. Under normal circumstances it would be hoped that both these people would know if the patient had an AHD. Where there is no relative involved, then the GP should be able to step in.

There may be an argument for the Act to require all GPs to know whether their patients have an AHD and if so to have a copy on file, electronically if possible. This would be especially important in the case of individuals like myself who are without family and who live alone. Even having an attorney for health matters could prove useless if no one knows who that person is. For such patients there is perhaps also an argument for the patient's GP to know who the patient's Trustee or Executor is. This information could then be shared with health providers.

- For those who wish to take out an AHD, education, if not legislation, will be the key to ensuring that GPs have on record those patients who do have an AHD. Indeed there are many people I have met who are not even aware that such a document exists, so there is a need for considerable public education on the existence of this option and the need to keep it updated.
- None of the above is of any immediate help if a person is unexpectedly admitted to a hospital unconscious or with impaired cognitive function through sudden onset illness or accident if a relative cannot be contacted. For those with no relatives, it may take some time for friends to become aware that something is amiss and even then, they may not be able to assist with

knowledge of the existence of an AHD. (Personal friends in the nursing profession have told me this is not an uncommon scenario). In an ideal world, everyone should carry with them or keep in their car an indication of who to contact in an emergency, along with information about blood type, known allergies etc but alas, we do not live in an ideal world.

- I would agree that multiple ways of enabling health care providers to become aware of the existence of an AHD would be better than having one system only. Of critical importance is the scenario for someone living alone who calls an ambulance but who has become unconscious before paramedics arrive. Paramedics must have the power to enter the premises and undertake a reasonable search for an AHD – eg. in the kitchen or bedroom.
- I cannot imagine the practical impact of the consequences of such an obligation placed on hospitals, facility management teams etc being great. An AHD is a document like any other in that it needs to be stored and readily retrievable whether in hard copy or electronic format. Any impact on professional decision-making should also be negligible provided that legislation (i) is tight, precisely worded and implementable in protecting the rights of care providers and (ii) does not give care givers decision-making powers they should not need to have.

#### Section 2.4

*Should a health provider be required to consult with an attorney appointed under an enduring power of attorney before forming a reasonable belief that a direction in an AHD is uncertain (consistent with the current legislation, to consult with an attorney appointed under an AHD)?*

- See comment above in 2.2.3 dot point one. In addition, If only two people are to consult on this, whoever consults with the appointed attorney should be the person in the team of medical care providers who has the greatest knowledge about the clinical situation; that is, a treating doctor should consult with the attorney rather than a registered nurse. Preferably, a decision should be made in the legislation about how many people should consult on this matter and who they should be.

*Should the protection for a health provider who does not follow a direction in an AHD because of changed circumstances be modified so that it is a valid reason only if the adult would have thought their direction to be inappropriate if they had known of the change in circumstances?*

- NO health provider should be able to make the decision single-handedly NOT to follow a direction because of changed circumstances – they should be required to participate in a consultation process similar to the one outlined in the preceding clauses relating to a direction being deemed ‘uncertain’. As indicated above also, providing treatment even in changed circumstances may not be without risk of outcomes that would be deemed undesirable by the patient.

*Should the protection for a health provider who does not follow a direction in an AHD because he or she believes it is inconsistent with good medical practice be omitted?*

- I suspect that in practice this is likely to be more difficult to implement. If such a decision in any way causes the health provider conflict with his/her religious or ethical beliefs, this may result in difficult if not tragic scenarios. Again here, a consultative process is warranted, as this may avoid the pressure and possible negative consequences of making a decision single-handedly, which, as above for ‘change in circumstances’ scenarios, is highly undesirable. If individual care givers were able to make one off decisions about whether to provide or withhold treatment, there would be little point in a patient having an AHD and little value in upholding common law rights.

For patients with AHDs, their autonomous choices and right to self-determination must be the priority. As the ALRC suggests, the situation must be viewed at all times from the perspective of the patient and not the care providers.

### Section 3

*Should the guardianship legislation be amended to ensure that common law rights to consent to or refuse health care are not affected by the legislation?*

- Absolutely. I am personally of the belief that it is **at least abuse, at worst a personal assault** to administer health care to someone who, when in full possession of their faculties and intellectually capable of understanding the consequences of their decisions, has given clear instructions about their health care, whether in common law circumstances or in a statutory AHD.

### Section 4

#### 4.1

- **Dot point one.** The substitute decision maker must have power of attorney though. Even if a substitute decision maker is a member of the family, he/she should have PofA. If not, then other family members must also be consulted to ensure there is consensus about withholding or providing treatment. If no consensus is possible, the decision should remain a medical one. Either way, a process of consultation must be undertaken.
- Likewise for **dot point four**, single-handed decisions made by anyone who does not have power of attorney are highly undesirable.
- **Dot point five** I would support.
- **Dot point six** I would support wholeheartedly. That face that there are people alive (?) today who have been of life support for many years is an affront to human dignity.
- **Dot point seven** I would also support.

#### Section 4.2

Agree.

#### Section 4.3.1

*Should any limitations on the effect of decisions about health care be more clearly stated in the body of the Act, rather than in a definition?*

- Yes.

*Should it be an offence to withhold or withdraw a life-sustaining measure without consent or authorisation when continuation or commencement of the life-sustaining measure would not be inconsistent with good medical practice?*

- Wouldn't this depend on what direction is in an AHD? If consent is not given, then yes, it should be an offence.

#### Section 4.5.1 **QLRC recommendation 11.3**

- My understanding of an AHD is that it outlines only a small number of life threatening medical circumstances. In the case of a patient who is in a terminal stage of life and they are mentally competent to refuse life sustaining measures, this should not be overruled by any statutory limitation. In the case of a patient who indicates in an AHD that they do not want life sustaining measures because they are going to die anyway, this too should not be overruled.

#### Section 4.6

*Should the limitation on when a direction in an advance health directive to withhold or withdraw a life-sustaining measure can operate be omitted?*

- Yes, provided no decision can be made unilaterally by any one individual and that a consultative process or some other mechanism is in place.

*Should the limitations on a direction to withhold or withdraw artificial nutrition or hydration be treated differently to other life-sustaining measures?*

- No.

#### **Section 4.7**

*Should the limitations on operation of a substitute decision maker's consent to withhold or withdraw a life sustaining measure be omitted?*

- Again, I think a consultative process is more desirable than the decision falling to one person, even if that person has power of attorney. So, perhaps there is an argument for 'consultation' to be the 'limitation' in such situations.

*Alternatively, if a substitute decision maker's consent cannot operate under s.66A of the GAA Act, should the legislation allow the health provider to refer the decision to the adult guardian to make a decision (if the adult guardian is the guardian for the adult, for the Tribunal to make a decision)?*

- Yes.

#### **Section 4.8**

*Should consent be required to withhold a medically futile life-sustaining measure?*

- No.

*Should consent be required to withdraw a medically futile life-sustaining measure?*

- Yes. Inasmuch as the measure was originally, when commenced, considered a valid treatment but is now not considered a valid action, some explanation may be warranted about how the situation has changed and why the measure, initially acceptable, is now no longer regarded the same way.

#### **Section 4.9**

*Should the Criminal Code be amended to remove any doubt that a health provider who withholds or withdraws a life-sustaining measure in accordance with the guardianship legislation is not criminally responsible?*

- Yes.

#### **Section 5.**

*Should the authority to provide urgent health care without consent to meet an imminent risk to life or health be clarified so that it is consistent with the authority to provide health care without consent to prevent significant pain or distress, that is, where it is not reasonably practicable to get consent from a person who could give it under the guardianship legislation?*

- Yes.

*Should it be possible to provide health care without consent to meet an imminent risk to life or health if the health provider knows that the adult objects to the health care in an AHD or reused the health care at a time when the adult had capacity to make decision about health care?*

- No. The provider just 'knowing' seems insufficient cause. Some evidence should be possible that backs up the provider 'knowing'.

#### **Section 6.1**

*Is it appropriate that registration of enduring powers of attorney is not required?*

- On the information provided in this Issues Paper, I would say 'yes'.

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