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Corrigendum to:

Submission to:

REVIEW OF ORGAN AND TISSUE DONATION PROCEDURES SELECT COMMITTEE

Four errors and omissions have been found in the submission that I lodged. I request that the following corrections be made in the submission or that this corrigendum is attached to the submission.

None of these changes materially alters the facts in my submission or the proposals that I have made.

Page 1, "Background", paragraph 3, last sentence

The sentence refers to a GCS score of "just one". This should read "just three".

It reads: When we were told the results of Sarah's first complete neurological tests, which registered a GCS score of just one (her pupils were reacting to some minor background brain activity being sustained by life support), we accepted that the situation was hopeless.

It should read: When we were told the results of Sarah's first complete neurological tests, which registered a GCS score of just three (her pupils were reacting to some minor background brain activity being sustained by life support), we accepted that the situation was hopeless.

Dr at Prince Charles Hospital, is willing to explain to the Committee that this is not a material difference.

Page 4, "The choice", paragraph 2, second sentence

The word "ask" is missing from the sentence.

It reads: If we reverse the onus for donation and make a mistake is it possible that someone could for an organ to be returned from the recipient?

It should read: If we reverse the onus for donation and make a mistake is it possible that someone could ask for an organ to be returned from the recipient?

Page 5, "My position", paragraph 4, third sentence

The word "safety" has been used. It should read "safely".

It reads: I went through that with my children when, through the schools program, they were taught how to safety ride their bikes.

It should read: I went through that with my children when, through the schools program, they were taught how to safely ride their bikes.

Page 8, "Contact details", Home email address

This is shown as:

It should be shown as:

Thank you,

Stephen Minslow

19 August 2008

Submission to:

REVIEW OF ORGAN AND TISSUE DONATION PROCEDURES SELECT COMMITTEE

Background

This submission is a result of a tragedy.

On 9 December last year my daughter Sarah decided to end her life. Sarah was an alcoholic. I will not detail the events surrounding her suicide here, but I am willing to be questioned by the Select Committee on the circumstances and the Select Committee may access her Death Certificate, the Coroner's Report and Police file on the matter if they see fit.

Following her suicide attempt Sarah was sustained on life support at the Prince Charles Hospital for five days until 14 December 2007. We had very little cause for hope in those days because the extent of Sarah's brain injury was severe. My wife is a Registered Nurse and spent some time specialising in the field of neurological science and she was honest in her assessment with me. When we were told the results of Sarah's first complete neurological tests, which registered a GCS score of just one (her pupils were reacting to some minor background brain activity being sustained by life support), we accepted that the situation was hopeless.

At that point we advised the Prince Charles Hospital that Sarah should be an organ donor. The reason why we did this spontaneously was that we have always had an open communication with our children and had discussed organ donation with them. Their views were shaped by ours and my explanation to very young children was, "When I die, take whatever others can use and put the rest out in the garbage". We are a family that believes that ashes to ashes and dust to dust is just a terrible waste.

The circumstances of our failure to achieve organ donation are recounted here because the experience made me determined to achieve a change.

- Dr at Prince Charles Hospital, pursued our wishes for Sarah to donate her organs. He advocated for us but was denied by the Hospital Administration who, having taken legal advice, refused to countenance any action.
- The reasons for their decision to refuse organ donation were not explained to us.
- In a sense of some frustration I sought independent legal advice on making an application to the Supreme Court.

- I was advised the next day, Friday 14 December 2007, that the definition of death was a medical, not legal test, and therefore a decision to pursue the matter through the Courts would depend on the weight of medical opinion.

- However I was also advised that provisions existed in the relevant legislation for Sarah to be an organ donor if a sibling was suffering from a terminal condition. My reaction to this was to ask who I should adopt. I was not joking.

- The crux of the matter, in the legal sense, was that even if I could find a Justice or a full bench of Judges who agreed with me they could not make a judgement. This is because the relevant legislation has made findings ultra vires, that is, beyond the power of the Court.

Upon receiving this decision, and there having been no change in Sarah's condition for five days, we requested that life support be withdrawn. Sarah died within a few hours. Her background brain activity could not sustain her respiratory system and progressive organ failure followed. In just a few hours we stood at her bedside and watch the precious gifts of her heart, lungs, kidneys and liver destroyed because Sarah was incapable of sustaining her life while we were frustrated from sustaining others.

And that was Sarah's death.

Every minute of the five days that she was sustained in Prince Charles Hospital was precious to us. I wouldn't give a minute back. I prayed for more time, for just a sign of hope that she might recover. But I was realistic and I knew that the situation was hopeless. It was just a shame that the State of Queensland didn't also realise that the situation was hopeless and help us give life.

That was when I decided that I had to change the law. This Select Committee has arrived with perfect timing for me.

What follows may seem a little disjointed but it represents a process of consultation and the forming of a view that what happened to me in my experience may not be shared by others. So I discuss the process of forming my view, not just the position that I take.

The issues

There are three key issues that we face when dealing with the dead and the dying.

The first is medical. We adopt words and practices that medical professionals have to follow in defining death. We do this in terms that will not conflict with their ethically with their patient. "Dealing ethically" depends on the values and beliefs of the individual. This means the patient, nearest family members and medical professionals alike.

Next is the law. If the Courts could deal with matters relating to the termination of life they would hear and weigh the medical and legal opinion represented before them. That is how the law and the Courts are supposed to operate and it is the basis for establishing legal precedent. The opinions presented will reflect the ethics of the parties to an action. Ethics or social mores shape society and are the ammunition for legal precedent. The law is inherently conservative and being heard in the Courts is the basis for formulating change. A Court may reject an argument but will give its reasons for doing so. This instructs us on the issues that have to be addressed to achieve change and to shape our society and its values.

The third issue is social. In social issues, key lobby groups compete for centre stage to represent their constituent interests. Social issues have greater potential to divide the community than most issues.

However, lobby groups will rarely represent the people who really deal with the social issue of death. These people, like me, who stand at a bedside and have to make the decision to withdraw life support or plead for it to be maintained. These people may not be represented in a debate and I do not claim to represent them. But I know they are grieving, disillusioned and frightened people. As the law stands at present they may be confronted with the horror of an unexpected death and the choice of making organ donation that they are not ready to give or with the desire to make an organ donation that they cannot achieve.

If legislation is passed to reverse the onus for donation it will face challenges. The law will probably deal with the significant religious and cultural groups but the disadvantage of some in these groups poses a grave risk of offence heaped on past offences. Additionally, in the broad community there are those who are not religiously or culturally represented but who just can't let go. There are also those who want to let go and give life to others. All of us are the people who attend graves to be close to those we should not have lost.

The choice

From December 2007 I have sought the advice of eminent doctors and lawyers and formed a view that the Spanish model, or reversing the onus for donation, could be the preferred model. However, in my research I found that a reversal of the onus for donation would place a burden on Aborigines to take a positive measure to preserve their cultural beliefs.

This troubled me because I understand the feeling and grief of Aborigines at having their culture overwhelmed by us, sometimes well meaning, but often careless and unfeeling. Given aboriginal mortality, dislocation and other significant social issues that they face in adapting to an imposed society, do they deserve and will they cope with another well meaning but poorly executed imposition on their rights?

For many Aborigines and other social groups their culture and social order has pre-eminence; it is sacred. If we reverse the onus for donation and make a mistake is it possible that someone could for an organ to be returned from the recipient? How would a Court make a judgement that an organ should be returned for burial and condemn the recipient to death? It is an untenable situation and it must not arise.

In January this year I corresponded with Professor of Bath University in the United Kingdom. I did not know at that time that Professor was campaigning against the very measures in the United Kingdom that the Select Committee is now considering for Queensland.

Initially Professor railed against my views as disregarding social order, of putting imperfect science and expedient law above social needs and in particular above the needs of ordinary people confronting tragedy and grief. After exchanges of correspondence he accepted that our position, in Sarah's circumstances, was our choice and that we should have been entitled to make it, but that no person or authority had the right to impose it on us.

And that is what formed the view that I express here. I started out not wanting to waste Sarah's potential to donate organs because life is precious. I worried about trampling on people's cultures and weighed it as a decision about "least worst choice". I arrived at a view that beliefs are precious to people and are shaped by their circumstances at a point in time and that people change their views and can be generous with the gift that their loved ones can give in death.

My position

A sustainable change

If it had not been for a tragedy I, like the majority of people, would be disinterested in the work of this Select Committee. Disinterest may be too kind a word. Apathetic is probably more appropriate.

Apathy is the cause of the remarkable statistic shown on page 19 of your Issues Paper, where 90% of Australians are comfortable with organ donation but only 37% of the population have actually registered to be an organ donor. The difference of 53% of the population represents the critical mass who are comfortable with organ donation but don't do anything about it. The reasons are apathy or possibly a state of permanent denial "it can't happen to me" so why sign up.

Societies experience of adjusting to new regimes for societal behaviour have been successfully moulded over recent decades in attitudes to drink-driving, smoking in the workplace, in public transport and restaurants and recently hotels. However, these bans and prohibitions have really only been effective because we have effectively educated society about the dangers. We have made it socially unacceptable to engage in behaviours that place others at risk.

So to achieve societal change and overcome apathy we should educate and we should be prepared to do it over the long-term. Marketing to enlist support for organ donation among the adult population will be a drawn out process.

Cultural change in society at large occurs at generational change and usually because of inter-generational communication, like you going home and discussing organ donation with your children, or visa-versa, them coming home from school and discussing it with you. This kind of discussion helps to form views which, over time, are adopted as strongly held personal views into adulthood.

The change starts at the registration of birth, and it permeates but is not insistent in religious and cultural education. You know that a change is underway when your children come home from school and seek your views and ask you to sign a consent form. I went through that with my children when, through the schools program, they were taught how to safety ride their bikes. But it's a mix of new forms of learning and old forms or learning. In my family we discussed the nature of life and death and organ donation with the passing of great-grandparent and then grandparents.

The measures currently proposed, to reverse the onus for elective donation, may be achieved in the next generation after effective marketing drives a vital shift in cultural views and moves people from apathy or denial to making a choice.

Immediate improvement in donor rates

I propose that the law should be changed to require that medical professionals request organ donation, in appropriate cases, irrespective of an entry on the donor register. The statistics show that apathy or some other indifference makes the donor register ineffective as a source of people's real position on organ donation.

From my consultations with intensive care professionals I have learned that they will accept the responsibility for seeking death-bed consent, but with some reservations about an additional responsibility in an over-worked environment. It is likely to become a key role for social workers and nurse managers and possibly with the support of hospital chaplains or clergy affiliated with the family. To counter the objections to the additional workload a request should be limited to cases where organ donation is viable. Where consent is obtained it should be in writing and obtained from the next of kin with the support of family members.

This has the potential to improve the quality of support for the family and is likely to produce positive outcomes for organ donation. My basis for this is my own experience and my beliefs which align with 90% of the population. Anything positive offered to a family facing the decision to withdraw life support from a loved one is made in an entirely different context than a decision to tick a box on a license or Medicare application.

Don't side-line the law

The medical profession can sustain "life" indefinitely but the issue comes down to what is life and what is death. We have sophisticated machines that can detect background brain activity consistent with the life support we use to sustain life. Is that life or is it sustaining the really dead? According to New York State in the United States my daughter Sarah was dead after two neurologists confirmed their physical observations after day three. Sarah's EEG showed the same level of background brain activity on day five of her life support as on day one.

The protocol says that assessments should be conducted on day one and day three to determine any natural or induced recovery and that is fair enough. It provides a reasonable time between assessments for the gravely ill to show any sign of recovery. There was no recovery but there was also no deterioration in Sarah's condition because of the quality of care she was given. Ultimately it was the machines that dictated the course of events because medical professional have become somewhat subservient to the machines that they helped design to sustain life, even in hopelessness.

As I stated earlier I was ready to go to the Supreme Court with medical professional support and seek a court order to take Sarah's artificially sustained life to theatre to harvest her organs. My legal advice was that, even if the Justices had agreed with me, they were powerless to make such a judgement. The law has made such judgement "ultra vires", beyond judicial power.

If we (you) are prepared to change the law to reverse the onus for organ donation you must allow that right to be challenged, and not just by next of kin and family but by members of society who claim a moral interest and want it tested at law.

In a situation where medical advice is that recovery is impossible and with the consent of a family willing to allow organ donation I propose that a Court be given the power to make a judgement to terminate artificially sustained life. Any such application must be made with agreement by medical practitioners that life is not sustainable without artificial support (i.e. medical intervention), that the family represented by the next of kin agree with the medical assessment and with a medial protocol that allows organ donation.

Conclusion

I urge you to consider the alternative incremental measures that I have proposed which:

- Aim at achieving awareness of the issue and therefore a cultural change in the next generation so the issue of reversing the onus for donation does not arise.

- Move the critical decision for organ donation to the hospital bedside and engage with the people confronted with the decision to withdraw life support so that something positive is offered at such a negative time.

- Give your judges the right to issue judgements where there is agreement between the medical profession and the people making the decision about life support.

Thank you,

Stephen Minslow

13 August 2008