Speech by

Miss FIONA SIMPSON

MEMBER FOR MAROOCHYDORE

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TRANSPLANTATION AND ANATOMY AMENDMENT BILL

Miss SIMPSON (Maroochydore—NPA) (9.21 p.m.): I move—

"That all words after 'Bill' be omitted and the following be inserted—

'be referred to the Legal, Constitutional and Administrative Review Committee for consideration and report back to the House by 1 August 1999.'."

The Queensland coalition will be seeking all-party support for a parliamentary initiative to find answers to the State's desperately low organ donor rate. The private member's Bill we are currently debating is well intentioned and certainly has raised debate of this very important issue. I believe that there are underlying flaws in the Bill, which I will outline later as well as some possible solutions.

We in the coalition believe that it would be a tragedy for this legislation to be simply voted down and the issue forgotten. Thus, in referring this Bill to a parliamentary committee to investigate Queensland's low organ donation rate we expect parliamentarians, in a non-party political way, to have input into the formulation of recommendations, be they administrative and/or legislative, for the benefit of the community we serve. The deadline reflects the community expectation that this issue be seriously considered and not relegated to the backburner.

Certainly, the Legal, Constitutional and Administrative Review Committee has the appropriate charter, resources and structures to investigate this matter and report back its findings as we search for workable solutions. Once again, I stress that the issue of Queensland's low organ donation rate is too important to be allowed to fall off the public stage. I believe that we have an opportunity to assist not only in the public education campaign but also in promoting an agenda to Government for appropriate action. Certainly some other States and countries are achieving better results than is Queensland. We all want to see lives saved, and that is why the coalition wants to see the Parliament come together on a matter that needs positive outcomes.

Most people will agree that there is a problem with organ donation rates. The issue has been thrown into greater relief as the success of Australasian transplantation has grown strongly. Breakthroughs in medical science mean that people who were once faced with a lifetime of incapacity or perhaps a greatly shortened lifespan now in many cases have new hope and new alternatives with transplant technology and more sophisticated drugs.

The success rates for heart and lung transplants, not to mention kidney transplants, have improved tremendously. I am sure that we all remember young Fiona Coote, who, as Australia's then youngest heart transplant recipient, bravely faced her heart transplant in 1984 and subsequently, after organ rejection, a second transplant in 1986. Of course, the stature of her surgeon, the late Dr Victor Chang, is legendary. Fiona Coote has been a tremendous ambassador for the cause of organ donation over the years.

Many people in Australia have received donated organs since that time, and other surgeons have performed what seems quite miraculous surgery. I pay tribute to some of our outstanding health professionals in Queensland who are part of that miracle. I find their skill and dedication quite outstanding and quite humbling.

Talking to people who have been successful organ recipients is an incredible experience. One heart patient, Jeff Lewis of Brisbane, whom I talked to in researching this Bill, described to me just how wonderful it is to have that second chance at life. In Jeff's own words—

"I have danced at my daughter's wedding, seen two grandsons and seven mango seasons."

However, Jeff said to me that he would rather have given that away than to see a family divided over organ donation. His belief is that families need to talk about this issue more and that greater education and funded promotion are two of the keys to improving organ donation rates.

The right of individuals to make choices is extremely important. However, the reality of death in a family and how that family comes to grips with it can be dramatically affected by how that family is notified and consulted at the time of tragedy. Families, too, have many long years ahead of daily reminders of missing people at the dinner table, so the grief experience should not be underestimated or treated flippantly when discussing organ and tissue donation. Depending on the circumstances, the grief of those left behind can have a real impact, even to the point of mental and other serious illnesses.

I have never had to approach a family to tell them that their loved one is on a respirator and legally brain dead and that they are a potential organ donor. However, I have talked to people who do this very difficult job sensitively and compassionately. They have a strong professional commitment to maximising organ donation. They describe the importance of the family in the process and how they are able to take their time explaining things. They say that a holistic approach is the best way, that it works best in gaining consent.

In the words of one of the State coordinators who has worked in this area longer than many members have been parliamentarians, they had never—not once—had a family refuse to give consent to donate a loved one's organs where the wishes of that person were known. It may happen, but where there is well-trained staff it is rare.

I found that extremely interesting, because it is obviously a myth of our society that families having the right to give or reject consent is the reason organ donation is low. That is not the case. The main problem is not grieving families overriding the wishes of their deceased loved ones to be organ donors where those wishes are known; the problem is that not enough people have indicated those wishes to anyone. Thus, removing the right of families to give consent—it should be remembered that "consent" is also their right to be notified before the removal of a dead loved one's organs—will not in fact address the serious problem of low organ donation rates.

Jeff and other volunteers who spend a lot of time talking to service clubs and community organisations also know that it is the families who become some of the greatest advocates of organ donation. They are needed, too, in the fight to raise awareness and to dispel the many myths. Get the families off-side by insensitivity or by taking a person's organs without talking to the family first, and the distress it is likely to cause and negative publicity, let alone the American experience of possible litigation, are guaranteed. In the words of Jeff, as well as those health professionals I have talked to who are at the coalface of organ transplantation: education is what is desperately needed, as well as better coordination and improved funding for promotion.

Let us look at some of the statistics on the current state of organ donation. In a 1997 Medical Journal of Australia article by Professor Graham J. Macdonald, donation rates of all organs in Australia have fallen from 231 donors in 1989—that is, 14 donations per million of population—to 184 in 1995, or 10 donations per million of population. As the journal notes, this is a level inadequate to keep up with new additions to the waiting list for organ donation.

I have talked about the sweetness of a second chance at life for those who have received organs. However, there is also the tragedy of those who wait and who die waiting. The journal states—

> "At the end of March 1996, 1699 people were on waiting lists for organ transplantation in Australia. This included 1555 waiting for kidneys but in the previous year only 441 renal transplants were performed, including transplants from living donors. The number of patients waiting for kidneys is larger because dialysis provides an alternative option not available for patients with end stage organ failure of heart, lungs and liver."

In a New South Wales study a number of years ago, it was found that, of 2,879 patients who had died in five hospitals, posthumously they were able to identify 73 potential donors, only 19 of whom had donated. The research showed that the reason for non-donation was that the patients were not being ventilated or there was a refusal by the next of kin. Together, this accounted for 43 of the potential donors. The issue of ventilation is, of course, critical.

At this point, I wish to talk about some of the processes involved in organ donation, because there are many myths. Certainly, the issue of people worrying about whether or not they would really be brain dead before their organs would be taken is one of those myths. There is a very stringent process in declaring someone brain dead and a potential organ donor. If a person is brain dead, they need to be ventilated to keep their organs sustained artificially, as I mentioned before. Thus, it is less likely that that person has been killed outright in a traffic accident and, more likely, that through serious injury or

some other condition they have been transported to hospital and, at some point, have been declared brain dead but their organs are able to be sustained artificially.

Of about 120,000 people who die of everything from old age to illness each year in Australia, only a very small number—1%— have the potential to be organ donors. A person basically has to die in a hospital's intensive care unit where they have been mechanically ventilated before they can even be considered as a potential donor. Brain death means that if the machine were turned off, the patient's heart would cease beating.

So what is the process in being declared brain dead? Two independent specialists are required to verify brain death. There is also usually a six to eight-hour wait before the deceased would go to theatre for the removal of organs. During this time, staff would talk to the family; the coroner may be involved, or there may be a police identification; the tissue typing and tests for diseases such as HIV are undertaken; and consideration must be given to the time that may be required to fly the organ to the recipient. If the organ cannot be used in Queensland, it would be offered interstate.

With tissue donation, for things such as heart valves and eyes, there is a bit more flexibility and a lot more potential donors because the donor does not have to be mechanically ventilated. The donor is more likely to have suffered a cardiac death. For tissue donations such as bone, tissues can be retrieved up to about 24 hours after death. And heart valves and eyes, I think, can be retrieved up to about 12 hours after death.

What are some of the potential solutions to Queensland's low donor rate and the low donor rate of many of the other States? I have already mentioned the need for greater education, not only of the public but of health-care professionals. And in their case, that requires fairly specialised training. There are resource issues as well. South Australia dramatically lifted its donor rate only after a significant funding increase for a more coordinated approach across the State.

It is very timely that this Bill has come on for debate tonight because only this week the inaugural forum of Australians Donate, the peak body for health-care workers and lay people with an interest in organ and tissue donation in Australia, met on Monday and Tuesday in Canberra. The forum drew together a wide range of interested parties, such as intensivists, donor coordinators, recipient coordinators and recipients and their families. I understand that it was a very successful event. Forum members will be seeking to draw up national strategies, because there was a strong consensus of the need for a national approach to this issue.

Queensland is not the only State with poor donor rates. Australian States all need to work together to improve the rate of organ and tissue donation, because our residents are sharing that very small pool of potential organs and tissues for a second chance at life. I understand that, over the next few weeks and months, Australians Donate will be formulating these strategies arising out of the forum workshops. These are some of the top people in their field, and I believe that we will be able to benefit from the ideas that they formulate. Of course, Queensland Health employees are involved in that process.

One issue that had prominence at the forum was again the call for education— education of not only the general public but of health professionals. That takes money and consistent systems and resources for ongoing training. Queensland currently has three organ donor coordinators, and I understand that, a few weeks ago, the Health Department advertised for a manager/coordinator of organ and tissue donation for Queensland. There has been a very successful program for a number of years to train critical care nurses, and I understand that there is talk of extending that more formally to other health professionals.

Certainly the issue of a national donor registry was discussed at the forum. If the House supports the motion tonight to refer this issue to the Legal, Constitutional and Administrative Review Committee, I believe that this group will be an important resource for Governments throughout Australia as we grapple with this issue. We may not agree on the effectiveness of this Bill at this point, but I hope that, as parliamentarians, across party lines and political divides, we can resolve to properly research this issue and report to Parliament with some better answers than we currently have.

As I have mentioned, there is a concern about the workability of this particular Bill in that it cuts the family out of the process of consent or even prior notification before taking organs. There are some other practical problems, such as the issue of informed consent, interaction with advance health directives and the integrity of the driver's licence database. However, the first question that we need to ask when analysing this Bill is whether it will fix the problem and whether it has any other unintended consequences.

The fact is that there are few organs available for donation. The Bill is based on the assumption that this lack of availability is because families are denying consent to donate organs when the wishes of the person are known, thus overriding those express wishes. Therefore, the Bill would make the information on a driver's licence about a person's wishes to donate their organs equivalent to consent, removing the prior notification or consent rights from the family. However, the evidence does not back

up the assumption upon which the Bill is based. I emphasise that the major problem is not families refusing consent where those wishes are known. Additionally, there are people who have marked "no" to organ donation on their drivers' licences because they have had a misconception about what was entailed, or they simply did not have the information available to them at the Transport Department counter to make that decision.

There is a tremendous need for all families to discuss this issue so that people's intentions are clearly known among family members ahead of time. There is also definitely a need for more money for effective promotion of the issue. Other issues that I hope LCARC would consider include a national donor register. Of course, we know that, in Victoria, the register has not been successful, but there are a number of reasons for that. We need a national donor register together with information on how to develop protocols with the Transport Department to give quick, legal and appropriate access to the driver's licence databank where information is stored about people's intentions in regard to organ donation.

I urge the House to support this motion. I urge parliamentarians to look at this as a bipartisan issue in which we do seek to bring a deadline to the parliamentary debate, as far as the consideration of this Bill is concerned, so we will consider it again. But it is most important that this issue is clearly broadcast in the community, that people discuss these issues and that the myths surrounding organ donation are once and for all dispelled. I commend the motion.