



Speech by

Hon. WENDY EDMOND

MEMBER FOR MOUNT COOT-THA

Hansard 14 April 1999

TRANSPLANTATION AND ANATOMY AMENDMENT BILL

Hon. W. M. EDMOND (Mount Coot-tha— ALP) (Minister for Health) (9.06 p.m.): The Government opposes this Bill not because of its intent but because of difficulties in its implementation. However, I sympathise with the very real concerns of the member for Thuringowa and I wish to assure him that the important issue he has raised is one of which the Government is acutely aware and actively trying to address. However, I am concerned that this Bill presents a simplistic approach to a very complex issue, that it does not address the main issues of transplant donations and that it introduces a range of difficult assumptions about informed consent. The Bill means that an indicative tick placed on a form when in a queue for a driver's licence becomes a binding legal document even retrospectively.

Honourable members interjected.

Madam DEPUTY SPEAKER (Dr Clark): Order! Honourable members will resume their seats.

Mrs EDMOND: Successful donation systems contain the following key elements—

- the ability to ensure that all potential donors are identified;
- the option of donation is offered to all eligible families;
- the option is offered in a sympathetic and appropriate way; and
- the donation is utilised to the maximum benefit.

The aim of the Bill is to give legal status to the indication on drivers' licences regarding organ donation. Under the proposal, if an individual were to make a positive indication on a driver's licence, there would be no further need for designated officers to contact the next of kin regarding consent. Although the Bill is an attempt to address an important issue, it deals only partially with one aspect—the identification of donors—of a very complex problem. As organ donation is an emotive issue, there are significant concerns among health professionals about circumventing the process of consulting with relatives of potential donors.

I wish to mention some of my concerns. The Bill makes the assumptions that nothing has changed in that person's life since the ticking of the box on his or her licence. Although there is a formal ability to revoke, that in itself assumes that each licence holder knows and remembers that fact. It is a serious decision in respect of which people need access to counselling and to be able to ask questions when making the decision, not merely in a queue for their licence or licence renewal. It introduces elements of retrospectivity in that a tick on current licences will have a completely new meaning. How the donor died may also affect the family's decision. The absence of a tick may not necessarily mean that the person does not wish to donate; it could mean that he or she has not made a decision or considered that option. Licences are not necessarily readily accessible to doctors and retrieval staff.

An indication on a licence provides an important guide to the deceased person's intentions regarding organ donation. Although this can assist the family in making a decision, it is not the major hurdle in obtaining donations. The current consent procedures under the Act allow for the suggestion to be proposed in a considerate and sympathetic way and are not considered to be the main contributing reason for the shortage of donor organs. About 85% of families approached consent to the use of their loved one's organs to extend another life, with most families respecting the deceased's intentions when they are known.

This private member's Bill does not effectively address the shortage of donor organs. The issue of declining organ and tissue donation is complex, but it is unlikely that the consent procedures under the Transplantation and Anatomy Act 1979 are a major reason for this. Comparisons of organ donation rates in countries where permission is assumed unless there is written opposition and other countries that allow donation only where written approval is given before death show that there is very little difference. Indeed, in 1992 research on this issue showed that there is no obvious correlation between organ donation rates and the existence of presumed consent laws. The more significant problems are the lack of coordination of and invitation to the organ donation process, with more than 50% of potential donor families not even being approached. Queensland also has the added hurdle that it does not permit the release of donor status data because of confidentiality provisions. However, Queensland Health is currently working with Queensland Transport to overcome these barriers. This Bill does not overcome the barriers; it does not even recognise what is described as the major hurdle to donor identification. The ultimate aim is to remove the technical barriers to optimise use of current donor information on licences.

Each year 5% to 20% of Australians on organ transplant waiting lists die before a suitable donor organ is found, depending on what organ is awaited. Members should be aware that access to organs is not strictly on a time waiting queue but depends on the critical need and closest compatibility match to the donor. In Queensland the organ and tissue donor rate began to decrease significantly during the early 1990s. There are a number of possible reasons for this, including of course the reduction in the road toll, the decrease in drowning rates as a result of the introduction of compulsory pool fences and the introduction of the mandatory wearing of bicycle helmets.

In Queensland 49% of donors died as a result of road or other trauma. Road trauma accounted for 32% and other trauma, 17%. Another 39% of donors died by cerebrovascular accident or stroke. Better surgical management and advancements in the treatment of hypertension have therefore also been identified as contributing to this decrease. There is also evidence that media reports of negative experiences of donor families and subsequent threats of legal action following organ removal saw a decline in donor rates. I have to say that this is a major concern that I have with this Bill—that the alienation of the families may lead to more damaging media and the impact that will have on donor rates in the future.

A recent US study showed that in-house coordination and routine notification of all hospital deaths resulted in an increase of 387% in organ donation in the targeted 25 hospitals. Conversely, a recent study from Europe, quoted in the Journal of the American Medical Association, finds no obvious correlation between high post-mortem organ removal rates and the existence of presumed consent laws.

Recent Australian and overseas research supports Queensland Health's strategies aimed at increasing the rate of tissue and organ donation. In May 1997 the Transplant Services Advisory Committee was constituted with the objectives of providing advice to the general manager on the present situation and how services can be enhanced with the focus on benchmarking; new developments and treatment; strategic directions of services, role delineation and planning; and human resource issues, particularly work force planning.

The Transplant Services Advisory Committee also saw a role in developing a framework which would enhance the organ/tissue donation rate in Queensland. In February 1998 TSAC endorsed the discussion paper *Queenslanders Donate—a new way forward*. The member for Thuringowa has stated that he wants to see action on this need and to set the ball rolling. It has. In September 1998 the Beattie Government brought down its 1998-99 Budget, which allocated over \$300,000 to implement an improved coordination service for organ/tissue donation.

Australians Donate met for the first time in October 1998 to develop a national level framework to improve organ/tissue donation rates across Australia. I consider it appropriate to await the outcome of the national forum of Australians Donate to ensure that the Queensland direction is consistent with the general principles of Australians Donate.

Queensland Health has formulated a range of strategies, known collectively as *Queenslanders Donate*, which will provide a structured and consistent approach to donation aimed at ensuring the key elements of donation are met; to further develop the transplant donor service in 16 major hospitals; to work with participating hospitals to maintain and increase the number of organ/tissue donors; to work more closely with the John Tonge Centre to maintain and increase the number of tissue donations and, while the focus of this Bill is on organ donation, there is a wide range of tissue, from bone to heart valves, that can be utilised to enormous benefit; to establish a single point of contact for referral when a death occurs in the coordinating hospitals; to provide a 24-hour referral evaluation and consent service; and to establish quality assurance and audit mechanisms. The present level of service to all other hospitals will be maintained.

Interstate data also indicates that there needs to be effective liaison between hospitals and donor coordinators and that coordination is a vital ingredient to ensuring success. *Queenslanders*

Donate will be established in accordance with the new initiative funding proposal agreed as part of the 1998-99 State Budget. The manager position has already been advertised and three coordinator positions are due to be advertised this month. Dependent upon the availability of suitable applicants, the service will be staffed and operational by June 1999, and these people will work closely with the present organ/tissue coordinators. The coordinators' roles will include liaison with community groups. This is a start and we will continue to search for ways to increase donations.

The importance of the donation of organs to needy recipients should not be undervalued. Australia's health care system allows a higher usage than occurs in many other countries. In 1997 there were 190 Australian organ donors. In 1998, 196 donors benefited 661 organ recipients. In Queensland 40 donors saved the lives of 145 recipients.

I have tried to outline tonight some of the strategies we are currently implementing to address in a sympathetic and positive way the key issue that the member for Thuringowa identified, that is, the shortage of organs available for donation. But we must never lose track of the sensitive fact that those donations come as a result of loss of life, usually premature loss of life, leaving a grieving and often traumatised family. I find it difficult to go out and say, "We must have more organ transplants", for to achieve that means we must have more young, healthy but dead people to give those organs.

To agree to the use of organs and tissues to enhance the lives of other individuals can be part of the grieving and the healing process—to see the good that comes from that ultimate generosity—but that agreement must be made willingly and needs a sympathetic approach and counselling, not reliance on a quick decision along with a licence application over a busy counter. Surely we all agree that such an important decision needs informed consent.

I am advised that if the private member's Bill were passed in its present form, Queensland Health would become de facto administrator of a person's body in that the department would determine if organ donation takes place, regardless of any next of kin or family consideration. The Government is therefore opposing this Bill for very sound reasons. Queensland Health and Queensland Transport are developing and implementing systems that will be acceptable to all stakeholders and will provide for the next of kin to remain part of the decision making process.

I understand that the Opposition may seek to refer this Bill to a committee. The Government will not oppose such referral. However, I am not prepared to sit back and wait for another six months or more of dillydallying. There have already been a number of reviews, both in Queensland and Australiawide. We think it is time for action.

This Government is already acting. I have set in place a number of actions to improve coordination of potential transplant donations. We will not waste time with review after review but will work with the Queensland centre of Australians Donate to maximise organ transportation rates in a considered and sympathetic manner. As such, through Australians Donate Queensland Health has indicated support for progress towards the establishment of a national register which would provide accurate data, stored appropriately and accessible only to authorised persons.
