

## **DRAFT SECOND READING SPEECH**

**HON GUY BARNETT MP**

### *Human Tissue Amendment Bill 2024*

*\*check Hansard for delivery\**

Madam Speaker, I move that the Bill now be read a second time.

The purpose of the Human Tissue Amendment Bill 2024 is to make contemporary amendments to the *Human Tissue Act 1985*. While these amendments are minor and technical, they will include the ability to give important recognition to those people who have given the ultimate gift of life in organ donation.

I acknowledge the advocacy of families, carers and loved ones regarding the technical barriers that were recently identified across Australia's organ donation and transplantation laws that have limited families' ability to share their loved ones' stories publicly.

Established in 2009, the Australian Government's Organ and Tissue Authority coordinates the DonateLife network in partnership with state and territory governments, DonateLife teams, eye and tissue banks, hospitals, health specialists and the community.

Impressively, the first 10 years of the national DonateLife network program saw a 122 per cent increase in deceased donation rates, resulting in an 81 per cent increase in people receiving an organ transplant.

Locally, DonateLife Tasmania coordinates all organ and tissue donation activities across the State. DonateLife medical and nursing specialists provide professional donation services within hospitals and encourage best practice to increase donation rates. Such is the success of this Tasmanian team that, while the 2023 national rate of consent to transplants was 55 per cent, Tasmania led the nation with an 83 per cent consent rate from families of potential organ donors.

Other DonateLife TAS activities include raising awareness about organ and tissue donation and offering care and support to donor families, including by facilitating community-based activities and events. Donor remembrance services and associated media recognise the gift of organ donation with donor families, which seek to promote organ and tissue donation.

It was the Western Australian Government that first raised concerns that the media activities of the DonateLife network had evolved beyond the four-decade old framework, which required strict confidentiality of donor identities.

In Tasmania, it was regrettably confirmed that the Human Tissue Act prevented DonateLife Tasmania from publishing the personal stories of deceased organ and tissue donors, even where such publication would be in accordance with the wishes of the donor's family who may wish to honour their loved one's donation in this way.

In the words of Bruce McDowell, Chairperson of Donor Families Australia, when he wrote to the Premier seeking amendments to the Human Tissue Act "We feel that it is a basic human right for families to be able to speak freely about their loved one as part of their healing."

Fortunately, unlike some other jurisdictions, Tasmanian donor families have not been prevented from sharing their stories personally, but these amendments acknowledge that these stories should have the full support of the DonateLife Network's resources.

Mr Speaker, today's amendments will acknowledge the lifesaving gift of organ donors and allow families to tell their stories and commemorate their loved ones and raising community awareness of, and increased participation in, the Australian Organ Donor Register and furthering the re-harmonisation of organ and tissue donation legislation nationally.

Before moving onto describing the other amendments, I would also like to acknowledge that approximately 1 800 people are on the waitlist for a transplant in Australia.

One organ donor can save the lives of up to seven people and help many more through eye and tissue donation. Online registration takes only a minute and can be done through the DonateLife website, MyGov or the Medicare app.

Mr Speaker, in preparing these amendments, a number of other technical issues and anachronisms were identified, to which I will now speak.

The Act currently allows for two medical practitioners to sign off on an emergency blood transfusion for a child where no parent or guardian is able to consent to that transfusion.

However, Air ambulance and rescue operations have come a long way since 1985 and it is now technically possible to administer blood transfusions during remote rescue situations.

Amendments will replace the requirement for two medical practitioners to endorse the decision to give a child a life-saving blood transfusion with a requirement for one medical practitioner and one paramedic. This reflects the crewing configuration of the aero-medical and medical retrieval services, known as the Air Ambulance, which predominantly involves a paramedic and doctor working on a rescue helicopter in remote locations.

A further amendment to the same section clarifies that a person who is under the age of 18 and who is capable of making their own fully informed and voluntary decisions about their health, would not have their wishes overridden by anyone.

It is now common for contemporary medical practices to empower children to make informed decisions about their healthcare to foster trust and promote well-being. In response to this evolving understanding of children's autonomy and rights, legal recognition of children providing their own consent to medical treatment is developing across Australia. Part of this process is the removal of outdated legislative barriers to persons under the age of 18 making decisions for and about themselves.

Several of the other amendments are for this purpose, including the removal of any references that assign different rights of consent to persons under the age of 18 who are married, from those who are not married. The amendments replace these references with appropriate capacity-based principles.

A new Division Seven in Part Two of the Act similarly frameworks the use of a child's tissue for approved medical research.

The Human Tissue Act currently allows for the donation of blood for therapeutic, medical, and scientific purposes with the consent of the adult donor or the parent of a child donor and the agreement of the child. These provisions are out of date because they do not allow a mature minor to consent to their own involvement.

The amendments are based on provisions in the equivalent Queensland legislation and will require that consent to research involving the removal of tissue from children should be sought in accordance with the *National Statement on Ethical Conduct in Human Research*.

The National Statement is an evidence-based protocol issued by the National Health and Medical Research Council, which is itself established under the Commonwealth Government's *National Health and Medical Research Council Act 1992*.

The National Statement, and thus the amendment provisions, require a medical researcher to engage with the child in a manner appropriate to that child's age and maturity, articulating when freely given informed consent may be provided by the child – and unlike the current Human Tissue Act, makes no linkages between a child's personal autonomy and their marital status.

I commend the Bill to the House.