

I would like to take the opportunity to provide comments on the Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023, based on my experience as the parent of a deceased donor.

My son Anthony died in March of 2017 and due to the circumstances of his death, we were able to offer his organs for donation and DonatLife then swung into action to identify suitable recipients. Anthony left behind both parents, an older sister, a twin sister, grandparents, aunts and uncles.

Several months later we became aware of a support group for donor families, Donor Families Australia (DFA) and I promptly signed up so I could be amongst others going through the same issues. I have since noticed many other support groups exist for donor families and recipients and their families such as Aussie Transplant Mates, Kidney Transplants and Donors Australia, Heart Lung Transplants, Donor and Recipients Group Australia and others I'm sure I haven't discovered yet. They are private groups and they provide a much needed and appreciated environment for sharing advice and experiences. They also provide social outlets with Christmas parties and dinners, newsletters, DFA has hosted conferences (I attended their Canberra conference several years ago) that bring together not just interested donors and recipients but also local and federal members of parliament with an interest in this area.

My concern with this legislation is that proposed section 58A along with the proposed subsections do not appear to allow disclosure of information within private forums comprising donor families and recipients. These are incredibly important outlets for sharing experiences around donation and transplantation and highlighting upcoming events, most recently the Donor Heroes Night in May in honour of organ and tissue donors.

My other concern with this legislation is the use of the term 'authorised family members' which comes across as too official and overbearing. It may be a good list but families come in many shapes and sizes and for the law to say that the aunt or cousin who had or has a really close relationship with a deceased donor or recipient cannot speak about them at a commemorative event is misguided and wrong. When families make the decision to get up and speak at a service of remembrance about their loved one, it is an unimaginably emotional experience and no-one should be excluded from that because they are not on some authorised list. Is this meant to be policed by DonatLife staff? That is not fair to them. They do a wonderful job and are incredibly kind and caring and should not be burdened with this.

I also feel that the comment made by Dr Anne Webster MP, Shadow Assistant Minister for Regional Health in relation to the 'large expansion of the list of authorised family members' is insensitive to donor families. This is a common-sense list of people most likely affected by the death of a family member and there is no justification for excluding for example the twin or other sibling of a deceased donor from giving any form of consent, provided they are aged over 18.

Thank you for your time and I hope my thoughts are useful.

Cheryl Hardiman