

SUBMISSION TO JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

Submitted By:

CATHOLIC ASSOCIATION FOR SPECIAL EDUCATION SUPPORT

General

This submission is provided by the Catholic Association for Special Education Support. Our association operates under the auspices of the Catholic Archbishop of Perth. We are a parent group who work with parents and carers of children with special needs and other Catholic Agencies to support children with disabilities to access a Catholic Education.

Our concerns regarding the proposed legislating of end of life choices centre around our focus on supporting children and their families and carers to reach their full potential and to be included, accepted, valued and participate in the community. They are also centred in a strong belief in the sanctity of human life and the unique contribution every individual can make to the lives of those around them and to their communities.

As a society our respect, care and support for the weak and the vulnerable in our community is one of the most significant measures of our humanity.

Much of the focus in the debate about euthanasia centres **around the notion of 'personal autonomy' but we are 'social beings'** and any death affects all those in the community connected to that person. We cannot and should not separate the interests of the individual from the interests of society as a whole.

We believe the focus of our community should be on assisting people to live; and at the end of life, providing appropriate palliative care to die with dignity. As a society we should be assisting the weak and vulnerable in our community by providing medical, physical, social and legal resources, as the means to live life to the fullest possible, not the means to end their lives.

We believe that there are sufficient provisions within the current laws to provide for people to make informed decisions about their end of life options and that irretrievable harm will be done to society, and the medical profession, if the laws were to be changed to allow for voluntary euthanasia or physician assisted dying.

Terms of Reference 1 – Current Practices

Currently in cases where there is a terminal illness people have a right to refuse medical treatment and in the case of extreme suffering the right to refuse the use of extraordinary measure to extend their lives. We believe these provisions to be sufficient, noting that refusing treatment is quite different to requesting assistance in dying.

In the case of terminal illness where there is excessive pain and no hope of recovery or relief, it is accepted practice to administer pain killers which may have the side effect of ending life.

As parents of children with disabilities we have seen and experienced the intense pressure exerted by medical professionals to terminate life in utero when tests reveal the possibility of

a child being born with a disability. We are concerned that legalised euthanasia will increase this pressure and in **time 'normalise' the taking of a life judged to be not worth living.**

We are painfully aware the **medical predictions are often not correct** and many of our children are evidence of misdiagnosed conditions and incorrect predictions. So many of our children have overcome their initial medical and intellectual challenges to achieve amazing results and live amazing lives.

In my own case, I was three months pregnant with my second child, when my first child was diagnosed with a disability (cerebral palsy) and I was advised to consider a termination. That second child is now a mother to four beautiful boys and a senior engineer with a major oil and gas company, having graduated from university with first class honours in science and mechanical engineering. The daughter with the disability now lives independently and works in open employment. Her presence in our lives has shaped our family for the better. She has taught us a lot about ourselves and our humanity and given much to the people in our community who have been part of her journey to independence. We as individuals and as a society are richer for her presence.

In the event of disability, through birth, sickness or misadventure, inevitably judgements are made about the value of life continuing and under the proposed legislation we fear the consequences of such judgements.

Already in Western Australia there are parent concerns as to the adequacy of the treatment that is offered by some medical experts to children with disabilities and parents learn which doctors to seek out and which to avoid when seeking medical treatment. - for example, when a child with Down Syndrome needed cardiac surgery and had to travel to Melbourne to access treatment.

An unintended consequence of legislative change may be additional pressure on people with disabilities and their families. As the financial, physical and emotional burden of dealing with the disability increases, **society's willingness to support and assist may be focussed more on eliminating pain and suffering through euthanasia**, than alleviating it, by providing appropriate support and palliative care.

Suicide amongst our young and vulnerable, including the elderly and disabled, is already a serious concern. Much public campaigning is happening around the importance of supporting people with mental health issues. These initiatives fly in the face of the assisted suicide approach of the Euthanasia debate.

We already have people with disabilities identifying fear and pressure to take their own lives for fear of being a burden on their families and society. This pressure will only increase, if euthanasia is legalised.

Terms of Reference 2 – Current Framework, Proposed Legislation & Other Jurisdictions

Experience from other jurisdictions reveals that it **is very hard to put 'limits' on access to euthanasia** without being discriminatory.

Overseas experience demonstrates that once assisted suicide/euthanasia is enacted there is a slow but predictable broadening of access from being for terminal illnesses to any form of pain. We see examples of people seeking to end their lives for a variety of reasons including conditions which could be alleviated with appropriate support – depression, pain, extreme loneliness, abuse and even being 'tired of life'. There are reported cases of people with dementia, a woman with tinnitus and two deaf twin brothers accessing euthanasia.

Evidence from around the world has shown that legislation has made people on the margins of society more vulnerable. Adverse effects on indigenous people, people with disabilities and the elderly have been observed.

In the Netherlands euthanasia is no longer restricted to competent adults, it is now available to children, newborn babies with disabilities, people with dementia and mental illness including depression. There are movements to extend the legislation to **people 'over 70 and tired of life' and those who feel they have 'completed life'**.

In Belgium and the Netherlands, people with disabilities, but not a diagnosed terminal illness, have died under euthanasia laws.

In Quebec, after just a year of legalised euthanasia, there are **calls for 'euthanasia on demand'**.

The Victorian legislation includes **68 'safeguards'**, indicating how risky and open to abuse assisted suicide and euthanasia is.

The Victorian legislation states disability 'does not satisfy the eligibility criteria for access to Voluntary Assisted Dying nor does disability exclude access' further adding to the confusion and complexity of the issue.

People with disabilities see euthanasia not as a choice but as a real threat.

Terms of Reference 3 – Legislative Change Required

We believe as a society we have a responsibility to respect and value all human life, and in our increasingly secular society this responsibility seems to fall increasingly on the medical and legal professions. We believe we need to support the medical profession to uphold their Hippocratic Oath, preserving and protecting the integrity of the profession and its focus on healing and protecting human life.

We need to fully consider the impacts of legislation on the health system and address issues such as clinical regimes, side effects of such regimes and the management of patient and community expectations,

What are the implications for our **health professionals**, when they move from having a philosophy of doing no harm to their patients, to one where they are **actively involved in the termination of their patients' lives?**

What impact will this have on patients' **confidence in the medical profession?** Already many parents of children with disabilities are fearful of the medical profession when their children with disabilities experience health issues, both those related and those unrelated to their disability.

Terms of Reference 4 – Role of Advanced Health Directives, Enduring Power of Attorney etc and Implications.

Many of us as parents have Enduring Power of Guardianship of our children and are concerned how these will be covered under any proposed legislation.

In summary as an association focussed on supporting children with disabilities achieve their full potential, we are strongly opposed to legislation that would be sanctioning the taking of life. We believe that:

- life is sacred, to be respected, nurtured, valued and protected.
- every individual has a unique value and contribution to make to society.

- the medical profession needs to be supported in adhering to their Hippocratic oath in doing no harm to patients.
- as social beings the life and death of every individual affects the lives of all those around them, family, friends, neighbours, colleagues, community – it is never just a personal autonomous decision to opt for suicide or assisted suicide.
- death is part of living and should be supported as living is, with respect, dignity and appropriate palliative care.
- much healing happens in the process of dying, not only for the person dying but for family and friends – reconciliation, forgiveness, loving acknowledgements, gratitude and grace.

Legalising euthanasia will pose a potential threat to people with disabilities feeling pressure to end their lives lest they be a burden on their families and society, undermining their confidence in the medical profession and undervaluing them and their place in society.

Mary Ballantine (Chair)
Catholic Association for Special Education Support