LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
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Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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Submission to Select Committee inquiry into the Voluntary Assisted Dying Bill 2023.

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MARY PORTER AM

Submission to Select Committee Inquiry into Voluntary Assisted Dying Bill 2023

Thank you for the opportunity to lodge a submission to this important inquiry.

As a former member of the ACT Legislative Assembly, 2004 to 2016, I identified the need to examine public attitudes in relation to end of life issues, and requests for Voluntary Assisted Dying, VAD, in Australia and elsewhere in the world, particularly Europe, in preparation for the ACT Parliament having the power to pass such legislation.

Prior to undertaking a study tour in Europe, I conducted community conversations regarding citizens and organizational responses to the question of what people desired at the end of their lives and whether the ACT provided adequate support and services to meet people's expectations.

As you are aware, at this time, the Territories did not have the powers to pass laws that enabled any form of VAD. Since that time barriers to Territories being able to enact such laws have been removed, hence the Bill that is before this inquiry.

In June 2013, I undertook a study tour to research aspects of the law and practice in relation to end of life issues in three countries in Europe, that is Switzerland, the Netherlands and Belgium, all of which have either legislated voluntary euthanasia or amended the penal code to allow assisted suicide.

As I reported to the Assembly post my study tour, in examining the different forms of legislation and codes I met with nearly 40 experts including members of the medical profession, lawyers, ethicists, parliamentarians, policy makers, and other stakeholders. I also undertook several site visits and examined the regulation and administration of the different models where they occur.

I was fortunate to also meet with palliative care practitioners and patients, those who were involved in developing and improving palliative care policy and advising Governments in this area.

I learnt about the long history of discussion and debate that had taken place in relation to end of life issues and the emerging debates in relation to calls to amend the legislation, particularly in Belgium. The role of palliative care in each country and the use of and validity of end-of-life directives, or Advanced Care Directives (and the role of medical practitioners in honouring those directives is also under discussion in Belgium).

Obviously, VAD legislation is part of a continuum of care and measures in relation to end of life, should not be seen in isolation.

Palliative services need to be properly resources and fit for the purpose developed. I was told by a senior official in the Federal Swiss Health Department, Canton representatives and a palliative care senior executive in Switzerland, that the law allowing assisted suicide preceded resources being made available to develop better palliative care services. I was told that palliative care is still not embedded in the curriculum of the trainee doctors and

nurses. At the time, the Federal Health Department and the cantons were working together on developing a Palliative Care strategy.

In the Netherlands, and Belgium, palliative care, palliative treatment, and hospice services exist side by side with the euthanasia legislation and regulation.

Palliative care and palliative treatment are seen as two different stages of a continuum in the Netherlands and Belgium. Palliative care is seen as a service one can access quite early in the process, where one can access home based or day hospice based, counselling, remedial massage, physio, pain management, social events, skills development, and a chance to consider end of life decisions. One oncologist describes this as “putting life into one’s day not days into one’s life”. Palliative treatment is seen as the treatment one receives in the last two weeks of life.

According to research in Europe, people who have been granted access to VAD live longer than those who just access palliative services, this seems to be due to the person being able to relax in the knowledge that that they have the choice to end their lives at a time of their choosing. Not all persons who have been granted permission to access VAD do in fact take that option, it’s the choice that is important.

I note that the bill before this inquiry is in relation to the provision of VAD 18 years and over. I believe that the question of amending the legislation to include those between 12 and 18 years of age, and possibly younger, with important provisos, could be examined as part of the review of this legislation at a later time.

It should be noted that, at the time of my study tour the Parliament of Belgium was conducting a joint parliamentary inquiry into possibly amending its VAD legislation to include young people aged 12 to 18, and those with a mental illness.

In 2014 The Belgium parliament amended their legislation, with appropriate safeguards, to give access to VAD for this age group. The Netherland followed with its amendments in relation to VAD for the same age group shortly thereafter.

When visiting Belgium, I met with Dr. Dominique Biarent Unité de Soins Intensifs Pédiatriques, Head of the intensive care unit at the Queen Fabiola Children's University Hospital, Hôpital Universitaire des Enfants Reine Fabiola. She said she supported the legislation being amended by the Belgium parliament to include young persons from 12 to 18 years of age as she believed that, in her experience, young people who are terminally ill mature very quickly, far beyond their chronological age. She maintained that terminally ill young people should have the choice to end their lives in consultation with their care team and their parents.

She related a story about one of her young patients, a 12-year-old boy, reliant on intensive care, to remain alive. She said this young person had told her he was missing his friends in the ordinary oncology ward and wanted to return there, so he could see his friends, and have a “normal meal” or just a “lolly”. He was informed that he would not live very long without remaining in intensive care, a fact that he was fully cognisant of. The young person, his care team, and his parents, met to discuss his request which was granted.

When this legislation is reviewed at a later date, it is important that that terminally ill young people are given a voice in the consultation. The review should also be informed by the examination of the outcomes experienced in jurisdictions overseas where their legislation allows minors the right to be part of the conversation and the right to choose VAD.

Meanwhile, the current provision of palliative services in the ACT should be examined as to their type, accessibility, and whether they meet the needs of terminally ill persons of any age, and at any time, during the persons illness, not only just before death.

As is true for other services, it should not be assumed that services suitable for one age cohort is suitable for another, for example palliative services for adults, particularly older adults, would not necessarily be fit for purpose for children, adolescents, and young adults.

Palliative services should be seen as being on a continuum in terms of the stage of one's life post diagnosis, and offer a range of services along that continuum, that is as an "outpatient", or "inpatient" of hospice care at different stages, and home-based palliative services.

A robust and well-resourced suite of palliative service is not an alternative to VAD, and neither is VAD an alternative to robust palliative services, it not an either-or question, rather it is necessary to provide both of an excellent quality.

Therefore, I recommend that: -

- The ACT Legislative Assembly inquire into the provision of palliative services in the ACT, their suitability for all age groups and at different stages of the lives of the terminally ill, particularly of children, adolescents, and young adults.
- Research should be undertaken in relation to the effect of enacting legislation enabling access to VAD for children, adolescents, and young adults, where this has occurred in other jurisdictions, particularly in countries where the legislation has been in place for some years.
- Research undertaken the provision of palliative services for this cohort, where legislation has been enacted to allow the above age groups access to VAD.
- The training and qualifications of the medical and allied staff should be examined to ascertain the level and adequacy of education in relation to VAD and palliative care, and palliative treatment, and that this education is enhanced, to enable services to be provided at an optimum level.

Thank you for this opportunity to s contribute to this important inquiry. I am available to appear before the committee in relation to the above either, preferably in person, or remotely if necessary.

Mary Porter AM