SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL Ms Suzanne Orr MLA (Chair), Ms Leanne Castley (Deputy Chair), Mr Andrew Braddock MLA, Mr Ed Cocks MLA, Dr Marisa Paterson MLA

Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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Committee Secretariat

Select Committee on the Voluntary Assisted Dying (VAD) Bill 2023

Office of the Legislative Assembly for the ACT

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Submission to the Inquiry into the ACT Voluntary Assisted Dying Bill 2023

Every week around 10 people meet-up in a Melbourne park and walk together as part of their healing program to process their bereavement. Members vary from week to week and conversation emerges naturally as people talk about their loss. The facilitator noticed that one participant never shared the story of her loss and asked her why. In hushed tones she shared, "I cannot talk about it because he died using VAD and I can't bear what the reaction of the others might be". It transpired that 3 other people in the group were mourning a VAD death, and they too felt they could not disclose this fact.

VAD stigma can be real and can also be imagined. Either way, the result is a person grieving a VAD death may feel unable to tell their story. Why does this matter? Telling the grief story helps make it real. It can take six or more months before we understand viscerally that our loved one is really gone and never coming back. Observing funeral rites helps us with this first task of grief and so does telling the story which we may have to do repeatedly before we can believe it. In fact, the crippling disorder of Prolonged Grief most often relates back to an inability to talk about what happened and acknowledge it as real.

Incorporating provision for bereavement support into the ACT Voluntary Assisted Dying Bill 2023 is an important addition that early versions of VAD legislation across other jurisdictions neglected. Griefline runs many bereavement support groups over

the course of the year and no VAD related participants approached us for support until we launched a VAD specific bereavement support group for Victorians in collaboration with Dying With Dignity Victoria.

Now we hear stories of quiet desperation, of being able finally to cry from grief and not from VAD logistics. Participants described the exhaustion of having "to fight for him to live, and then fighting for his right to die". They found this advocacy role very isolating in the lead up to the death and then felt unable to talk about it afterward. Group members were able to recognise "me-too" moments, connect compassionately with each other, and felt themselves growing in empathy. Participants relayed how they received opinions, pushback, and judgements from people – in place of what they might normally receive as carers in such heightened circumstances, such as love, care, support, understanding, practical help. These opinions and criticisms heralded from both family members and professionals.

While we may imagine that perhaps in five or ten years VAD will be normalised and the stigma but a distant memory, the Canadian experience has shown that this is not the case – some thirteen years after the introduction of MAID what we are seeing is many more people accessing it, but no reduction in stigma within sections of the community. Recently one grandmother in Toronto was surrounded by her extended family and let them know she was choosing a MAID death. All but one got up, turned their back on her and walked out. No matter how accepted VAD may become by medical practitioners and the palliative care world, families like this one will continue to exist and that one isolated family member who stood by their grandmother deserves to be supported in their grief.

As more people access VAD, we expect the need for VAD specific bereavement support to rise in tandem. Unresolved grief lies behind many mental difficulties (suicidality, addictions including to substances and gambling, acts of violence and aggression and sometimes leading to street homelessness and incarceration). By incorporating VAD specific bereavement support into the legislation, you can ensure the wellbeing of the brave advocates who walk alongside their dying friend or family member.

At Griefline we have recently been approached by a person choosing VAD for group support in coming to terms with their own death. Ordinarily we would expect the Palliative Care setting to be most suitable for Dignity Therapy however this person has had a very negative experience in palliative care – when she spoke with the

support people that come to her home about potentially accessing VAD she was threatened with the removal of support 'we will report you to the service and you will not be able to access any further support'. She wants a space to talk about her impending death and what it means to her.

We would invite you to consider the psychological needs of people choosing VAD where they are unable to access therapy through Palliative Care b funding a service external to palliative care to provide eg a Meaning Focussed Therapy group for the dying which has worked so well in Canada.

In summary we invite you to include in the legislation provision for two very important services which in the normal course of events are offered through palliative care but in a VAD related death, our experience is, are not (or may not be the best place for them):

- VAD specific bereavement support
- Meaning Focussed or Dignity Therapy for the person choosing VAD

Sincerely,

Kate and Marianne

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Chief Operating Officer Clinical Services Manager

https://griefline.org.au/