

10 April 2017

## Voluntary Assisted Dying Bill

This short Carers Victoria submission highlights responses from a carer perspective to selected proposals outlined in the 'Voluntary Assisted Dying Bill Discussion Paper'.

Carers Victoria makes this submission with the understanding there will be many other individuals and organisations better placed to provide specific responses to many of the medico-legal questions around each proposal.

Carers Victoria's submission focuses on its position on those proposals which are considered most pertinent to people in care relationships.

### Care relationships

Care relationships are multifaceted and dynamic. There are 239,100 primary carers in Victoria:

- 66 per cent are women and 34 per cent are men
- 41 per cent care for their partner
- 29 per cent care for their child (including adult children)
- 21 per cent care for their parent
- 9 per cent care for another relative or friend, and
- 37 per cent report having a disability themselves.<sup>1</sup>

Female carers are more likely than male carers to provide a significant level of care, with 43 per cent of female carers providing over 40 hours of care per week, compared to 34 per cent of male carers. Carers who provide a significant amount of care often have a caring role for extended periods of time, with over one-third of primary carers having provided care for 10 years or more.<sup>2</sup>

### The importance of care relationships

The Victorian *Carers Recognition Act 2012*<sup>3</sup> (*the Act*) defines a carer as a person who provides care to another person within a care relationship because the person has a disability; or is older; or has a mental illness; or has an ongoing medical condition (including a terminal or chronic illness) or dementia.

The Act further specifies a person is not in a care relationship with another person merely because he or she is the spouse / partner, parent, child or other relative of the other person; or lives with the person.

The Act includes a set of principles about the significance of care relationships, and specifies obligations for state government agencies, local councils, and other organisations interacting with people in care relationships. Carers Victoria believes these obligations would apply to Victorian health services and health professionals assisting people with care needs to end their life.

As identified in Victoria's end of life and palliative care framework,<sup>4</sup> care relationships are a key factor in maintaining people with life-limiting conditions at home, within their communities and supporting people to exercise choice over their place of death. Given the significance of care relationships throughout people's lives and at the end of their lives, the needs of carers of people seeking assisted dying must be recognised and supported in the draft Bill.

### **Recommendation One:**

*Carers Victoria recommends the draft Bill makes reference to the Carers Recognition Act 2012 and its principles recognising the importance of care relationships at end of life.*

### **Requests free of coercion and family violence risk**

Carers Victoria supports the safeguards outlined for ensuring requests for assisted dying are voluntary and free of coercion; however, Carers Victoria also recognises additional safeguards may be required for people experiencing family violence. A diagnosis of a terminal illness and/or engagement with palliative care services does not necessarily mean emotional, physical or sexual abuse ceases.<sup>5 6</sup>

While the burden of disease caused by intimate partner violence towards women is well-recognised,<sup>7</sup> there is little data on the incidence of abusive relationships amongst the population of men and women at the end of life whom the Bill is proposed to apply to.<sup>8</sup> There were no recommendations arising from the Family Violence Royal Commission for services for people at the end of life.<sup>9</sup> The proposed new criminal offences may prove difficult to lay charges against or proceed with once the person has died. These charges may be unlikely to act as effective deterrents to some perpetrators of family violence who have exercised power and control over another person for long periods of time.

As identified in the Act, the fact of being a partner or relative of a person with care needs does not mean a person is a carer. However, prevalence data on family violence or elder abuse rarely distinguishes between abuse in the context of the range of family relationships and abuse within care relationships. There is some evidence to show:

- Some carers have their own physical and mental health conditions which result in their capacity to provide adequate care being impaired.<sup>10</sup>
- Intergenerational cycles of abuse and intimate partner violence can be experienced over many years. Older women are significantly more likely to experience mistreatment than older men.<sup>11,12</sup>
- A victim / perpetrator dichotomy is at odds with complex family and social circumstances within which people experience the need for care. For example, carers may find themselves with little choice but to provide care to the perpetrator, or roles can be reversed where a former perpetrator experiences abuse at the hand of the former victim.<sup>13</sup>
- Carers frequently experience abuse from people receiving care who have a severe mental or cognitive impairment.<sup>14,15,16</sup>

### **Recommendation Two:**

*Carers Victoria recommends that in addition to a psychiatric evaluation to assess decision-making, a risk assessment for family violence is conducted to assist in the identification of any coercion to seek assisted dying.*

### **Bereavement support for carers and families of people receiving assistance to die**

Caring for someone at the end of life can have a profound impact on subsequent bereavement experiences. Research suggests there are bereavement experiences and support needs which are specific to carers providing end of life care. Grief issues related to the carer experience include: strong links between the nature of the death experience, feelings of guilt and poor bereavement outcomes for some, as well as the experience of a 'void' created by the withdrawal of professional support after death.<sup>17</sup>

Carers frequently identify unmet communication and support needs both before and after bereavement. Evidence confirms carers and other family members would benefit from immediate post-death contact from a member of the care team, to offer comfort to the bereaved and to answer any questions or concerns relating to the death.

The term complicated grief describes grief which appears to deviate from the norm in duration and symptom intensity. Risk factors<sup>18</sup> for complicated grief include:

- stigmatised death e.g. suicide
- concurrent other loss e.g. death of another relative or friend, loss of paid employment
- low level of material resources e.g. income, savings
- age and gender e.g. being an older widow
- poor physical health
- previous unresolved grief and emotional reactions of anger, bitterness and intense guilt
- conflicting or ambivalent relationship with the deceased, and
- lack of social support.

Given these risk factors, carers bereaved following their relative or friend's illness and assisted death may be vulnerable to experiencing complicated grief. This may in turn increase their vulnerability to suicide and/or seeking assisted death if they are subsequently diagnosed with a life-limiting illness.

#### **Recommendation Three:**

*Carers Victoria recommends all carers and family members of the person assisted to die are offered bereavement support through palliative care services, in order to monitor and address complicated grief.*

#### **Recommendation Four:**

*Carers Victoria recommends data collection that will enable comparison of the rate of complicated grief experienced by this bereaved group with those bereaved after a person received palliative care services but who was not assisted to die.*

#### **Additional safeguards for vulnerable people**

Carers Victoria endorses expressions of concern by disability advocacy groups regarding vulnerable people with disabilities and the need for additional safeguards for a range of vulnerable groups.

Caring can have profound social, physical, emotional and financial effects for carers and their families. Females are more likely to take on caring responsibilities and the often intense and protracted nature of the caring role can leave female carers without income, savings or secure housing. Female carers and former carers need to be recognised as a vulnerable group experiencing additional disadvantage, leading to poor outcomes across a number of life domains including complicated grief, anxiety and depression, and post-traumatic stress disorder.<sup>19</sup>

Based on the experience in overseas jurisdictions where assisted dying is legal, female former carers with end of life care needs may be more likely to seek assisted dying in order to relieve family and friends from burden. In Switzerland 39 per cent of people assisted to die reported their need for long-term care as a reason for seeking assisted suicide.<sup>20</sup> Assisted suicide was more likely in:

- cancer diagnoses
- women
- people living alone, and
- older divorced people.<sup>21</sup>

A key recommendation from this population based study in Switzerland was for de-identified registration of assisted suicides, including data on patient characteristics and underlying comorbidities, so trends can be monitored.

In other jurisdictions, the rate of women choosing assisted death is nearly four times the rate of women who suicide unassisted.<sup>22</sup> The decision to seek assisted death can be strongly linked to women's social and economic disadvantage, and cultural mores valuing feminine self-sacrifice. Safeguards should ensure women's decision-making autonomy is genuinely protected, rather than creating conditions which encourage self-sacrifice through assisted dying.

**Recommendation Five:**

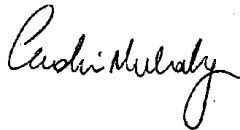
*Carers Victoria recommends data collection on people requesting assisted dying should include:*

- *Age and gender*
- *Primary diagnosis and co-morbidities such as complicated grief, anxiety and depression, and post-traumatic stress disorder*
- *Reasons for seeking assisted death*
- *Care relationship status – does the person receive support from family and friends?*
- *Carer status – is the person a current or former carer?*

*This will assist in monitoring whether some groups of people are more likely to seek assisted death, along with the individual and societal factors influencing this final decision.*

If you would like to discuss any of the Carers Victoria recommendations in this submission further, please contact Senior Policy Advisor, Anne Muldowney, on 0447 990 078 or [Anne.Muldowney@carersvictoria.org.au](mailto:Anne.Muldowney@carersvictoria.org.au)

Yours sincerely



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- <sup>1</sup> ABS, (2015), Disability, Ageing and Carers, Australia, Victoria, Catalogue # 4430.0
- <sup>2</sup> <http://www.carersvictoria.org.au/Assets/Files/CV%20Victorian%20Gender%20Equality%20Strategy%20submission%20March%202016.pdf>
- <sup>3</sup> [http://www.legislation.vic.gov.au/Domino/Web\\_Notes/LDMS/PubStatbook.nsf/edfb620cf7503d1aca256da4001b08af/023a825c23e20790ca2579c7000fb0bb/\\$FILE/12-010abookmarked.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/edfb620cf7503d1aca256da4001b08af/023a825c23e20790ca2579c7000fb0bb/$FILE/12-010abookmarked.pdf)
- <sup>4</sup> <https://www2.health.vic.gov.au/about/publications/policiesandguidelines/end-of-life-and-palliative-care-framework>
- <sup>5</sup> <http://www.theage.com.au/victoria/terminally-ill-women-left-in-care-of-abusers-mishandled-by-loved-ones-mission-20150623-ghvcpu.html>
- <sup>6</sup> The abuse you don't see <https://open.abc.net.au/explore/104026>
- <sup>7</sup> <https://www.vichealth.vic.gov.au/search/the-health-costs-of-violence>
- <sup>8</sup> [http://www.melbournecitymission.org.au/docs/default-source/position-papers/melbourne-city-mission-submission\\_royal-commission-into-family-violence.pdf?sfvrsn=0](http://www.melbournecitymission.org.au/docs/default-source/position-papers/melbourne-city-mission-submission_royal-commission-into-family-violence.pdf?sfvrsn=0)
- <sup>9</sup> <http://files.rcfv.com.au/Reports/Final/RCFV-All-Volumes.pdf>
- <sup>10</sup> Brandl, B., & Raymond, J. (2012). Policy implications of recognizing that caregiver stress is not the primary cause of elder abuse. *Generations*, 36(3), 32-39.
- <sup>11</sup> Biggs, S., Manthorpe, J., Tinker, A., Doyle, M., & Erens, B. (2009). Mistreatment of older people in the United Kingdom: Findings from the first national prevalence study. *Journal of Elder Abuse & Neglect*, 21(1), 1-14.
- <sup>12</sup> Killick, C., Taylor, B. J., Begley, E., Carter Anand, J., & O'Brien, M. (2015). Older People's Conceptualization of Abuse: A Systematic Review. *Journal of elder abuse & neglect*, 27(2), 100-120.
- <sup>13</sup> Kosberg, J. I. (1998). The abuse of elderly men. *Journal of Elder Abuse & Neglect*, 9(3), 69-88.
- <sup>14</sup> Ayres, M. M., & Woodtli, A. (2001). Concept analysis: abuse of ageing caregivers by elderly care recipients. *Journal of advanced nursing*, 35(3), 326-334.
- <sup>15</sup> Cooper, C., Selwood, A., Blanchard, M., & Livingston, G. (2010). Abusive behaviour experienced by family carers from people with dementia: The CARD (caring for relatives with dementia) study. *Journal of Neurology, Neurosurgery & Psychiatry*, 81(6), 592-596.
- <sup>16</sup> Vaddadi, K. S., Gilleard, C., & Fryer, H. (2002). Abuse of carers by relatives with severe mental illness. *International Journal of Social Psychiatry*, 48(2), 149-155.
- <sup>17</sup> Harrop, E., Morgan, F., Byrne, A., & Nelson, A. (2016). "It still haunts me whether we did the right thing": a qualitative analysis of free text survey data on the bereavement experiences and support needs of family caregivers. *BMC Palliative Care*, 15(1), 92.
- <sup>18</sup> Pilar Barreto-Martín, Marián Pérez-Marín and Patricia Yi (2012). Predictors in Complicated Grief: Supporting Families in Palliative Care Dealing with Grief, *Contemporary and Innovative Practice in Palliative Care*, Prof. Esther Chang (Ed.), InTech, DOI: 10.5772/30873. Available from: <https://www.intechopen.com/books/contemporary-and-innovative-practice-in-palliative-care/predictors-in-complicated-grief-supporting-families-in-palliative-care-dealing-with-grief>
- <sup>19</sup> Ibid
- <sup>20</sup> Fischer, S., Huber, C. A., Furter, M., Imhof, L., Imhof, R. M., Schwarzenegger, C., ... & Bosshard, G. (2009). Reasons why people in Switzerland seek assisted suicide: the view of patients and physicians. *Swiss medical weekly*, 139(23), 333.
- <sup>21</sup> Steck, N., Junker, C., Maessen, M., Reisch, T., Zwahlen, M., & Egger, M. (2014). Suicide assisted by right-to-die associations: a population based cohort study. *International journal of epidemiology*, 43(2), 614-622.
- <sup>22</sup> George, K. (2007). A Woman's Choice? The Gendered Risks of Voluntary Euthanasia and Physician-Assisted Suicide. *Medical law review*, 15(1), 1-33.