



**LEGISLATIVE ASSEMBLY**  
FOR THE AUSTRALIAN CAPITAL TERRITORY

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SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL

Ms Suzanne Orr MLA (Chair), Ms Leanne Castley (Deputy Chair),

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## Submission Cover Sheet

### Inquiry into the Voluntary Assisted Dying Bill 2023

**Submission Number:** 042

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# CarersACT



**SUBMISSION TO THE ACT GOVERNMENT  
ON THE INQUIRY INTO THE VOLUNTARY  
ASSISTED DYING BILL 2023**

**DECEMBER 2023**

## About Carers ACT

Carers ACT is the leading body for carers in the ACT. We work to ensure that carers enjoy improved outcomes in health, wellbeing, resilience and financial security. We also work to ensure that caring is acknowledged and recognised as a shared responsibility of family, community and government.

Our purpose is to support, connect and empower carers to maintain their caring role and personal wellbeing.

The Carers Recognition Act 2021 (ACT) recognises the value of carers and the care relationship and defines carers in the following way:

*“A person is in a care relationship with another person if the first person (the carer) provides care to the other person for 1 or more of the following reasons:*

*(a) the other person has a disability;*

*(b) the other person has a mental disorder or mental illness;*

*(c) the other person has an ongoing medical condition;*

*(d) the other person is aged and frail;*

*(e) the other person is a child or young person, and the carer is a kinship carer or a foster carer for the child or young person.*

Carers include family members, friends, relatives, siblings, or neighbours.

In the ACT more than 50,000 people provide care. Carers provide an important role in the family and in the broader community, supporting the quality of life of the person they care for. A carer’s role can include help with daily living activities such as: health care, shopping, meals, housework, transport, reading and writing, emotional and mental health support, and personal care.

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## Summary of Recommendations

1. Ensure the Bill upholds the rights of carers in accordance with the *Carers Recognition Act 2021* (ACT).
2. Insert a definition of ‘carer’ and the care relationship into the Bill. This should refer to the *Carers Recognition Act 2021* (ACT).
3. Insert “*provide protection for contact persons, carers and families who choose to assist, or not assist, individuals to exercise the option of ending their lives in accordance with this Act*” (or similar statement) into the Objectives of the Act.
4. Insert “*The role that carers play in supporting individuals accessing end of life treatment is vital and should be acknowledged*” (or similar statement) into the Principles of Act.
5. Recognise carers as an integral part of the care relationship at a time when an individual is choosing to end their life.
6. Ensure the Bill upholds the rights of carers to be respected and recognised as someone with knowledge of the person receiving care, in accordance with the *Carers Recognition Act 2021* (ACT) and the *Carer Recognition Act 2010* (Cwth).
7. Ensure that the Bill recognises and promotes the role of unpaid carers in the decision-making process by legislating that health practitioners be required to consider the care dyad.
8. Include the care dyad as a topic to be covered by the mandatory Voluntary Assisted Dying (VAD) training and qualification requirements for all health practitioners.
9. Incorporate an anti-discrimination clause into the Bill to protect carers from societal judgement or discrimination related to their involvement in VAD.
10. Develop and carefully implement tailored public awareness campaigning to overcome societal misconceptions of carers involved in supporting an individual accessing VAD.
11. Mandate carer awareness training be undertaken by all staff of the Care Navigator Service.
12. Integrate carer specific supports into the Care Navigator Service. Support must include both practical and emotional supports throughout the entirety of the VAD process, including bereavement.
13. Ensure the Bill upholds the rights of carers to have their social wellbeing and health recognised in matters relating to the care relationship, in accordance with the *Carers Recognition Act 2021* (ACT).
14. Ensure the Bill upholds the rights of carers to be provided with support that is timely, responsive, appropriate, respectful and accessible, in accordance with the *Carers Recognition Act 2021* (ACT).

## Introduction

Carers ACT welcomes the opportunity to consider the ACT Government's Voluntary Assisted Dying (VAD) legislation. Given the fundamental role of carers in supporting individuals with conditions that result in intolerable suffering, carers will naturally play a vital role in VAD processes and must be adequately considered in the relevant legislation and in its practical application in the ACT.

A carer's role can reasonably be expected to entail navigating emotional complexities surrounding end-of-life decision making, overseeing the logistical arrangements required to access VAD, advocating for the individual's wishes, and ensuring that throughout the process, the individual's daily care needs are met. By virtue of the care relationship, there is also a high likelihood that a person's carer will assume the role of 'contact person' as defined in the Voluntary Assisted Dying Bill 2023 ('the Bill') in instances where the individual has made a self-administration decision. The serious responsibilities held by this position further emphasise the need for carer consideration.

*Education and awareness of the centrality of carers within VAD processes, is paramount in protecting the rights, perspectives and welfare of both the individual seeking VAD and the carer who supports them. This is the basis of our submission to*

THE ACT GOVERNMENT ON THE INQUIRY INTO THE VOLUNTARY ASSISTED DYING BILL 2023

## Objects, principles and important concepts

It is reasonable to assume that a vast majority of individuals at the point of accessing VAD will have people in their lives providing care for them who are not paid professionals; this is a care relationship as defined by the *Carers Recognition Act 2021* (ACT). As such it is imperative that the Bill reflects the rights of carers outlined in the *Carers Recognition Act 2021* (ACT).

We note that while carers have been referred to within the Bill, no definition has been included. Clearly defining carer within the legislation is a crucial step to acknowledging the role of carers in supporting terminally ill people, as well as promoting engagement with carer terminology that encourages better identification of carers, leading to improved access to carer supports and services.

We also draw attention to the Objects of the Act (Section 6), which includes providing protection for health practitioners assisting individuals seeking VAD, however there is no mention of protecting a carer or contact person. Given the significant responsibilities of someone appointed as a contact person and the presence of liability offences if they fail in their duties, the objects of the Act must not only include protections for health practitioners but contact persons also.

Likewise, the Principles of the Act (Section 7) should include a statement recognising the contribution of carers and their significant role in the VAD process. Even when not acting as a contact person, carers of an individual accessing VAD are likely to be required to manage additional care duties; arranging supplementary appointments and transport, facilitating discussions with healthcare professionals, participating in the decision making process, supporting care recipients to understand and complete paperwork, all while also tending to the person's comfort, wellbeing, daily care tasks and working through the strong emotions that accompany a decision to access VAD. This role should be acknowledged by a statement in the principles of the Act.

## RECOMMENDATIONS

1. Ensure the Bill upholds the rights of carers in accordance with the *Carers Recognition Act 2021* (ACT).
2. Insert a definition of ‘carer’ and the care relationship into the Bill. This should refer to the *Carers Recognition Act 2021* (ACT).
3. Insert “*provide protection for contact persons, carers and families who choose to assist, or not assist, individuals to exercise the option of ending their lives in accordance with this Act*” (or similar statement) into the Objectives of the Act.
4. Insert “*The role that carers play in supporting individuals accessing end of life treatment is vital and should be acknowledged*” (or similar statement) into the Principles of Act.

## Carers as participants in decision-making

While respecting that the decision to end one’s life is deeply personal and ultimately must be the decision of the individual, there is no denying that carers are an integral part of the of the decision-making process alongside the person who is dying. Carers often possess crucial information about the individual’s care, preferences, medical needs and daily routines, making their involvement and insight essential for continuity of care. As such, carers must be treated as an integral part of the care relationship at a time when an individual is considering the choice to end their life.

The proposed Bill notes that “*an individual is capable of making a decision if they are capable of making the decision with adequate and appropriate support*”. The nature of the care relationship means that this support is likely to be facilitated in some degree by the individual’s carer.

The *Carers Recognition Act 2021* (ACT) supports carer involvement in discussions pertaining to the individual being cared for, stating that carers should “*be respected and recognised as someone with knowledge of the person receiving care, including during changes to the care relationship*”. Federal carer legislation is also clear on this topic of carer involvement, with the *Carer Recognition Act 2010* (Cwth) stating that “*Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers*”.

To acknowledge the important role of carers in VAD decision making, it is not only imperative that the Bill promotes carer involvement, but that health professionals involved also acknowledge carers. Health professionals must recognise the care dyad (where the carer and the person they care for are treated and seen as a unit), so that decision making is a supported and joint process with appropriate consents in place. Respecting the care dyad is an important part of ensuring VAD processes do not contribute to causing undue stress, harm or complex grief, and instead support the parties to come to terms with the decision being made. For this to occur, the care dyad should be acknowledged within VAD legislation and included as a topic in the mandatory training and qualification requirements of health practitioners opting to be involved in VAD.

### RECOMMENDATIONS:

5. Recognise carers as an integral part of the care relationship at a time when an individual is choosing to end their life.

6. Ensure the Bill upholds the rights of carers to be respected and recognised as someone with knowledge of the person receiving care, in accordance with the *Carers Recognition Act 2021 (ACT)* and the Carer Recognition Act 2010 (Cwth).
7. Ensure that the Bill recognises and promotes the role of unpaid carers in the decision-making process by legislating that health practitioners be required to consider the care dyad.
8. Include the care dyad as a topic to be covered by the mandatory VAD training and qualification requirements for all health practitioners.

## Access to supports

Further to reducing the risk of undue harm and complex grief, it is important to consider the negative social discourse and stigma faced by carers supporting individuals accessing VAD. Even throughout the recent discussions regarding VAD in the ACT, we witnessed vulgar misconceptions in public discourse about the role of carers; judgements that carers would force their own values on a suffering individual and prevent them from accessing VAD, through to notions that carers would coerce an individual into VAD to “get out of” their caring responsibilities or to fast track inheritance. These misconceptions are damaging and isolating, and combatting these erroneous beliefs are vital to ensuring the wellbeing of the carers and families of individuals electing to die through VAD. Incorporating an anti-discrimination clause into the Bill to protect carers from societal judgement or discrimination related to their involvement in VAD will help to establish a strong advocacy base for situations where public discourse is damaging, particularly where media is involved. Overcoming these societal misconceptions will also require careful and well executed public awareness campaigning.

Prior recommendations regarding mandatory carer awareness training being completed by professionals engaged in VAD will also help to dispel myths and promote a more accurate understanding of the vital contributions of carers.

Carers ACT also advocates for staff of the Care Navigator Service to undertake mandatory carer awareness training, and for carer specific supports to be integrated into the function of the Care Navigator Service. The integral role of carers in traversing supported decision-making and VAD logistics, paired with the high probability that many will take on the responsibilities of contact person warrants the need for specialised carer guidance and support. This support should cover both the practical and logistical aspects of VAD, as well as the psychological. Assistance to navigate the profound emotional and delicate ethical considerations must also be considered and should include separate, yet parallel supports for the individual and the carer separately to enable both to resolve their feelings and speak openly and honestly about fears and concerns. Support must be available throughout the entirety of the VAD journey and include bereavement care and considerations.

When designing the Care Navigator Service, it is important that the *Carers Recognition Act 2021 (ACT)* is reflected in its design, particularly the care relationship principles which state that carers should “*have their social wellbeing and health recognised in matters relating to the care relationship*” and “*be provided with support that is timely, responsive, appropriate, respectful and accessible*”.

## RECOMMENDATIONS:

9. Incorporate an anti-discrimination clause into the Bill to protect carers from societal judgement or discrimination related to their involvement in VAD.
10. Develop and carefully implement tailored public awareness campaigning to overcome societal misconceptions of carers involved in supporting an individual accessing VAD.
11. Mandate carer awareness training be undertaken by all staff of the Care Navigator Service.
12. Integrate carer specific supports into the Care Navigator Service. Support must include both practical and emotional supports throughout the entirety of the VAD process, including bereavement.
13. Ensure the Bill upholds the rights of carers to have their social wellbeing and health recognised in matters relating to the care relationship, in accordance with the *Carers Recognition Act 2021 (ACT)*.
14. Ensure the Bill upholds the rights of carers to be provided with support that is timely, responsive, appropriate, respectful and accessible, in accordance with the *Carers Recognition Act 2021 (ACT)*.

## Conclusion

The indispensable role of carers in coordinating the care required for an individual who is intolerably suffering while overseeing the logistical arrangements of VAD processes, participating in decision-making conversations, and advocating for the individual's wishes underscores the critical need for their inclusion in the legislation and its practical implementation.

The recommendations within this submission aim to safeguard carer rights and promote the support and recognition of carers within the framework of VAD legislation, however it is important that consultation does not end there. Such new legislation must be proactively monitored, reviewed, and adapted to address emerging challenges and concerns.




We welcome and look forward to the ACT Government opening further discussions regarding decision-making capacity and advance care directives, as this is an area of stress for carers hoping to honour the end-of-life wishes of those they care for and was noted as the strongest area of discussion in the YourSay VAD Listening Report. While we acknowledge that access to VAD for people who have lost decision-making capacity will be reviewed after the legislation has been in operation for three years, we expect a progressive government such as the ACT would be open to reviewing this sooner. Particularly as research emerges from other countries, including Canada, the Netherlands, Switzerland, Columbia and Belgium, who all have clauses regarding access of VAD for people who have lost decision making capacity within their legislation.

Carers ACT will actively seek to understand the experiences of carers in the VAD system as the legislation is implemented, paying particular attention to the support offered through the Care Navigator Service, the social stigma and misconceptions that carers face and importantly, how onerous supporting an individual through a three-request process is for the Carer.

*Carers ACT welcomes further opportunity to participate in further discussions or to provide advice on Carer issues, including the care dyad to assist the ACT Government in progressing it's VAD legislation and policy.*



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