

**CarersACT**



**CARERS ACT POSITION STATEMENT:  
VOLUNTARY ASSISTED DYING IN THE ACT**

**April 2023**

# Carers ACT Position Statement: Voluntary Assisted Dying in the ACT

## 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 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 housework, transport, health care, shopping and meals, reading and writing, emotional and mental support and personal care.

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## Introduction:

Carers ACT notes the opening of consultations on a proposed Voluntary Assisted Dying (VAD) Bill in the ACT and acknowledges that the ACT Government has invited comment on the draft discussion paper. We acknowledge that Carers ACT has engaged in a number of roundtable consultations leading to the submission of this paper.

Carers in the ACT provide an important role supporting family and friends who are frail aged or experiencing chronic ill health and through the palliative journey. While caring can be a rewarding and positive experience, it can also impact a carer's wellbeing and we are advocating for carers input, wishes and experiences to be considered and valued in the development and realisation of the laws about VAD.

Carers ACT is not providing a direct response to the questions raised in the Discussion Paper nor are we taking a position in relation to the availability or eligibility of VAD in the ACT. Carers ACT will be limiting our views to a set of principles that focus on recognising and supporting carers through the process of VAD. We have based these principles on advocacy, research, consultations and engagements with carers over many years and they replicate the principles of best practice in carer engagement and support.

Principles:

- The principles of the ACT Carers Recognition Act 2021 are upheld and carers are active participants and engaged in decision making.
- Carers receive access to support before, during and after the administration of the process of application and administration of VAD.
- The process of VAD should not unduly impact or affect carers by causing additional burden or harm.
- Carers are protected in the process of applying for and administering voluntary assisted dying.

## Discussion:

### **The principles of the Carers Recognition Act 2021 are upheld and carers are active participants engaged in decision making:**

Acknowledging that the choice to end one's life is a decision for that person, we believe that under the ACT Carers Recognition Act, carers must be seen as an integral part of the care relationship at that time and be recognised and respected through the process, including in the decision making. We support a process where the carer is actively engaged in discussions by health professionals alongside the person who is dying. We support a process whereby the care dyad (the carer and the person they care for) are treated and seen as a unit and that decision making is supported, where appropriate consent is in place, as a joint process. We ask for a process that does not result in undue harm or complex grief to the carer. For this to occur carers need to be involved in the discussions and decisions and have a sense of peace with the decision made by the person who is dying. The Carer Recognition Act 2021 supports this principle by identifying that carers views must be respected. We are not advocating that carers have a right to make the decision on behalf of or for the person

who is dying but we are supporting the recognition and engagement of the care dyad in conversations about palliative care and dying.

**Principle: Carers receive access to support before, during and after VAD.**

In the Discussion Paper section 2.2 The process for request and assessment, we are pleased to see the statement: ‘A person and their family, friends and carers should also be supported to navigate that process during a difficult time.’ The diagram that follows includes carers only in the very first step and in relation to the eligible person exploring the option. We would like to see that recognising and supporting carers to navigate the entire process is incorporated into the training and skills of the health professional and/or the health team so that carers are supported from the start of the process and through the various stages. Should this occur within the role of the suggested option of a Care Navigator Service we would be strongly advocating for that service to be supporting the carer through the various stages and not only providing an option at the start of the process. Whilst we strongly support that the care dyad is actively engaged throughout the process, we also recognise the need for separate yet parallel support for the person dying and the carer separately to enable both to resolve their feelings and speak openly and honestly about their fears and concerns.

**Principle: The process of VAD should not unduly impact or affect carers by causing additional burden or harm.**

Understanding the existing emotional and physical impacts of caring for someone who is seriously ill and dying, we are additionally mindful of the added stress and administrative tasks that may be required with a VAD process. We would like to ensure that the system, health professionals and the team such as the proposed Care Navigator Service are able to ensure this doesn't occur. We are concerned that should the process be overly complex, requiring multiple steps, appointments, health professionals and service providers, extended time periods, that there will be additional impact on the carer in terms of time, emotional and physical support, transport and administration of appointments and the like. This at a time when impact is already high and emotionally charged is likely to negatively impact on the carers health, wellbeing and finances during their caring role and beyond. It is also likely to be a contributing factor to the development of complex grief as it robs the carer of the choice of how they spend their time with the dying person.

Carers ACT is also concerned that provisions for conscientious objection will impact the ability for VAD to be administered in the person's home or hospice facility. With several residential aged care facilities and the ACT hospice facility being operated by religious based entities we are concerned that people residing or using these spaces will be required to leave in order to administer VAD. This would be highly distressing for carers, families and the person dying and would force choices about the location of where VAD is administered, and the person dies. The impact on the carer to support the dying person to move home or location would be profound.

## **Carers are protected in the process of applying for and administering voluntary assisted dying:**

Carers ACT would like the law and process to be very clear so that carers can confidently continue in their caring role during the administration of VAD without fear of legal or other repercussions. This is particularly relevant where the administration of VAD occurs in the carers home.

## **Conclusion:**

Carers ACT welcomes the passing of the Restoring Territory Rights Bill and the subsequent opportunity for the ACT to develop voluntary assisted dying laws. We wish to see the discussion, future laws and processes around VAD to include carers in line with the ACT Carers Recognition Act 2021 and our approach and principles reflect this.

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