



**PARLIAMENT OF VICTORIA  
STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES**

**Inquiry into End of Life Choices**

**Carers Victoria Submission 31 August 2015**

## About Carers Victoria

Carers Victoria is the state-wide peak organisation representing people who provide care. We represent more than 700,000 family carers across Victoria – including people caring for ageing parents, children with disabilities, and partners with mental illness or chronic health issues.

Carers Victoria is a member of the National Network of Carers Associations, and the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership based organisation. Our members are primarily family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

This submission was prepared by Anne Muldowney, Policy Advisor, Carers Victoria

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*“Grieving carers come from all walks of life and an infinite range of care situations. They may, for example, be parents coping with the diminished abilities and life choices of a child with a physical or intellectual disability. They may be family members dealing with the uncertainty, stress and sadness of watching their relative struggle with a debilitating mental illness. They may be daughters and sons, husbands, wives, lovers, friends and others adjusting to their loved one’s gradual loss of their personality or independence due to strokes, head injuries, AIDS, Parkinson’s, Alzheimer’s or other diseases. One thing they share in common is that they all experience loss at different times and in different ways as their caring journey unfolds.”<sup>1</sup>*

## Introduction

As the above quotation states, grief and loss for carers is by no means confined to the period immediately leading up to and following the death of the person they care for. Increasingly, people who are dying will have experienced very long periods of illness or disability prior to death and many of them will be in care relationships of long duration.<sup>2</sup> In this brief submission, Carers Victoria aims to contribute to the Committee’s assessment of the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care. We acknowledge the Committee’s commitment to investigating the meeting of community expectations and will address this from the perspective of carers and the people they care for.

The majority of people report that they wish to die at home but most people actually die in hospital.<sup>3</sup> Although the role of carers in supporting people’s preferences for end-of-life care is widely recognised, carers describe the role as “the hardest thing we have ever done”.<sup>4</sup> In order to assist a person to exercise their preferences for the way they want to manage their end of life, greatly improved recognition of and support for carers is required.

## About carers

Women are more likely to have caring responsibilities than men. 70 per cent of all primary carers are female<sup>5</sup>. Nearly 40 per cent of all carers are between the prime working ages of 45-64 years, and the ratio is even higher for female carers at 46.2 per cent. When caring is protracted, many carers feel they have little choice but to drop out of the workforce with significant consequences for family income during and after caring and reduced capacity for former carers to re-enter the workforce.

Primary carers are often in the caring role for extended periods of time:

- Over a third (34.1 per cent) of primary carers have been caring for 10 years or more.
- More than half (58.4 per cent) of primary carers care for 20 or more hours per week, with 38.9 per cent caring for 40 or more hours per week
- Of the 299,300 primary carers who provided care for more than 40 hours on average per week, 28,400 primary carers (9.5%) had been providing care for more than 25 years.<sup>6</sup>

<sup>1</sup> Carers Victoria (2011) *An unrecognised grief: loss and grief issues for carers. A worker’s guide.*

<sup>2</sup> Penrod, J., Hupcey, J. E., Baney, B. L., & Loeb, S. J. (2010). End-of-life caregiving trajectories. *Clinical nursing research*, 1054773810384852.

<sup>3</sup> Carers Australia (2014) *Dying at home: Preferences and the role of unpaid carers.* A discussion paper on supporting carers for in-home, end-of-life care.

<sup>4</sup> Palliative Care Australia (2004), Carers and end-of-life position statement

<sup>5</sup> Australian Bureau of Statistics (2012) Survey of Disability, Ageing and Carers

<sup>6</sup> Ibid

With an increase in the incidence of people living with chronic health conditions such as Chronic Obstructive Pulmonary Disease (COPD) and degenerative conditions such as dementia, a significant percentage of carers have provided care for many years prior to the person's death.<sup>7</sup>

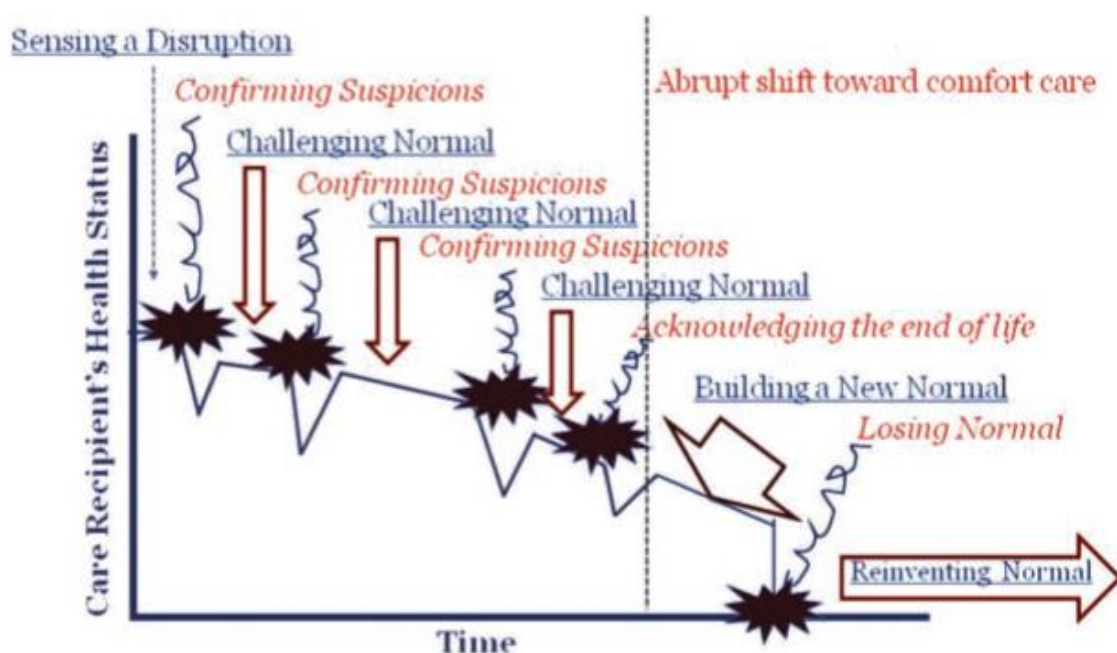
## The impacts of caring

The Committee will have reviewed evidence that the causes of death and typical patterns of illness leading to death have changed dramatically, often characterised as:

- Trajectory A : Short period of evident decline (mostly cancer)
- Trajectory B: Long-term limitation with intermittent serious episodes (mostly heart and lung failure) and,
- Trajectory C: Prolonged decline (mostly frailty and dementia).<sup>8</sup>

What often seems overlooked in these very useful trajectory types are the needs of people caring for people with different types of illness. For each trajectory, periods of decline for the dying person are matched by periods of increased intensity of caring and the need for constant adjustment, which researchers have described as a process of 'seeking normal'.<sup>9</sup>

**Figure 1: The expected end-of-life caregiving trajectory<sup>10</sup>**



The complicated nature of this graphic representation of the caring journey through end of life demonstrates there are many points along the trajectory that carers would benefit from support to assist them to make necessary adjustments while maintaining their own health and wellbeing.

<sup>7</sup> Penrod, J., Hupcey, J. E., Baney, B. L., & Loeb, S. J. (2010). End-of-life caregiving trajectories. *Clinical nursing research*, 1054773810384852.

<sup>8</sup> Swerissen, H., & Duckett, S. (2014). *Dying well*. Melbourne: The Grattan Institute.

<sup>9</sup> Penrod, J., Hupcey, J. E., Shipley, P. Z., Loeb, S. J., & Baney, B. (2012). A Model of Caregiving Through the End of Life Seeking Normal. *Western journal of nursing research*, 34(2), 174-193.

<sup>10</sup> Penrod, J., Hupcey, J. E., Baney, B. L., & Loeb, S. J. (2010). End-of-life caregiving trajectories. *Clinical nursing research*, 1054773810384852.

## Improving end of life choices

Carers frequently report they feel the weight of family and community expectations to provide care for people at home and a key factor in this is the lack of choice regarding alternative care provision.<sup>11</sup>

Carers Victoria considers that the choices of people approaching end of life and their carers are currently heavily constrained by lack of access to end-of-life care planning and palliative care services.

The Victorian Auditor General's Office (VAGO) reported on their audit of the Department of Health and Human Services (DHHS) Strategic Directions and care in four public palliative care services in April 2015.<sup>12</sup> VAGO has made 12 recommendations to address the major issues identified in the audit. Section 4 deals with support for carers and concludes that in spite of the significant strain borne by carers and families, support for them in their caring role remains inadequate. Improving access to services such as respite and psychosocial support for carers of people with a terminal illness remains a major priority.

DHHS has accepted the recommendations and prepared an action plan detailing how it intends to address them. DHHS also needs to review patient and carer reporting and after-hours service provision.

Priority areas include:

- Improved access to overnight respite care
- More timely and flexible carer support
- Reviewing access to and quality of after-hours support
- Improved access to bereavement support

The report highlights that supporting the care relationship is frequently a lower priority than supporting the individual patient and that sufficient focus on the needs of carers paradoxically only occurs when the caring role is over, i.e. when the carer is bereaved.

The report states that "Inevitably, despite respite being recognised as a significant need, palliative care services prioritise care for patients needing medical attention over the needs of carers." and that "Health service staff advised of instances where patients were admitted to inpatient services near death because their carers were unable to cope." This is problematic in the context of the Carers Recognition Act (2012)<sup>13</sup> which states that carers should have their social wellbeing and health recognised in matters relating to the care relationship. There is a pressing need for respite care to be recognised by palliative care services as support for the patient and the care relationship, not only as a support for carers.

VAGO recommendations to improve support for carers include that DHHS:

- conducts a systematic review of respite and carer support provision
- develops clear expectations for health services to appropriately support carers
- reviews and improves the after-hours model for community palliative care services across Victoria.

Carers Victoria fully supports all of these recommendations.

<sup>11</sup> Australian Bureau of Statistics (2012) Survey of Disability, Ageing and Carers

<sup>12</sup> Victorian Auditor-General (2015, April) Palliative Care Report. Melbourne

<sup>13</sup> State of Victoria, Carers Recognition Act 2012

Carers Victoria also advocates that the practice of assessing the needs of carers, as well as the needs of patients, should be routine in Victorian palliative care services. There is good evidence<sup>14</sup> that use of carer needs assessment tools can deliver benefits to carers through a change in health service practice that is facilitated by practitioners but carer-led. Used routinely, carer assessments can standardise assessment and support, facilitate delivery of carer-identified support and enable more effective targeting of resources.

## Legislation

Carers Victoria fully endorses the Victorian government policy of improving access to and the practice of advance care planning within the Victorian health system. Carers Victoria has reviewed the Victorian government's Advance Care Planning framework "Have the Conversation" which states that advance care planning is implemented within Victoria's current legal framework including:

- The Medical Treatment Act 1988
- The Guardianship and Administration Act 1986

However despite references to the importance of involving families and carers in advance care planning, it does not refer to the Victorian Carers Recognition Act (2012) and the obligations of public service care agencies to take into account the views of the carer when decisions are made that impact on the carer and the care relationship and to recognise the carer's own health and wellbeing.<sup>15</sup>

A benefit of including carers in advance care planning is to make explicit that carers have needs in their own right and that these are not necessarily always subordinate to patient needs.

## Recommendations

In reviewing recommendation 16\* of the 2009 Who Cares? Report<sup>16</sup> of the Australian Parliament's inquiry into better support for carers, Carers Victoria believes that there is scope for the Victorian government to take a leadership role nationally in raising public awareness around the use of advanced care directives such as Powers of Attorney and on the process of developing and communicating advance care plans:

### **\*Recommendation 16 (Who Cares? Report)**

*That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing and the Attorney-General fund a national information campaign to raise awareness about the need for, and benefits of, enduring powers of attorney and advanced care directives in the general community and among health and community care professionals.*

### **Palliative Care Victoria recommendations**

Carers Victoria is a member of Palliative Care Victoria and supports and endorses the recommendations contained in their submission to this inquiry.

<sup>14</sup> Stajduhar, K. I., Funk, L., Towe, C., Grande, G. E., Aoun, S., & Todd, C. J. (2010). Part 1: Home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998-2008). *Palliative medicine*, 24(6), 573-593.

<sup>15</sup> State of Victoria, Carers Recognition Act 2012

<sup>16</sup> Commonwealth of Australia (2009). *Who cares...? Report on the inquiry into better support for carers*. House of Representatives: Standing Committee on Family, Community, Housing, Youth. Canberra:

In addition, Carers Victoria makes the following recommendations to better support carers to enable people's preferences for end-of-life care:

1. That the health system and medical community support a dual focus on the preferences of both the dying person and their carer(s) in line with the Victorian Carers Recognition Act.
2. That the health system and medical community recognises carer rights to exercise choices about their role in supporting the preferences for end-of-life care of the dying person, particularly regarding choice of place of death, where this requires the support of a carer.
3. That the Victorian Department of Health and Human Services fund additional hospice care to enable the dying person and their carer(s) to exercise viable choice around a place of death other than home or hospital.
4. That the Victorian government acts on the recommendations of the Auditor-General to greatly improve the access to and quality of respite care and after-hours support in community palliative care services across Victoria.
5. That the Victorian government works to improve the capacity of Victorian workplaces to offer flexible support to carers of people who are dying.
6. That the Victorian Minister for Health and Attorney-General initiate discussion with their state and territory and federal counterparts regarding a national information campaign on advanced care directives and advance care planning.
7. That the Victorian government investigates ways of ensuring that caring for someone at end of life does not result in financial disadvantage during or after the caring role.
8. That the Victorian Department of Health and Human Services funds access to bereavement support for all members of caring families who require it.