

Public hearing, Melbourne 1 May 2013

Dear Senators

Carers Victoria is the state-wide peak organisation representing more than 700,000 family and friend carers across Victoria. Carers Victoria is a member of the National Network of Carers Associations and of the National Aged Care Alliance.

Care provided by family and friends is the backbone of Australia's community aged care system. Carers also make significant contributions to the lives of residents in aged care facilities.

Carers Victoria made a brief submission to the Committee based on previous submissions made by us in regard to modifications to the Aged Care Act and Principles and focused on three main areas:

1. Compatibility with the Carer Recognition Act (2010)
2. Principles for residential aged care
3. Principles for home care packages

Carers Victoria submits that the Living Longer Living Better Bill must be consistent with principles contained in the Carer Recognition Act (2010). The Act includes a ten point Statement for Australia's Carers and is complemented by a National Carer Strategy with six priority areas for action. The Act's core principles include:

- *Carers should be acknowledged as individuals with their own needs within and beyond the caring role.*
- *The relationship between carers and the persons for whom they care should be recognised and respected.*
- *Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.*
- *Carers should be treated with dignity and respect.*

I have chosen to highlight *Principles 5 through 8* as these are particularly relevant to the ways in which the Aged Care Act should specify obligations for approved providers. These principles relate directly to the treatment of individual carers of people receiving aged care services and recognition of their care relationships by approved providers.

It is Carers Victoria's position that relationships of care and support between family members and friends are some of the most significant and enduring in all our lives. This does not change when a person commences using funded community aged care services or enters residential aged care.

Carers Victoria research (*Still Largely on the Outside*) has found that following entry to residential aged care, family and friends can find it difficult to maintain a meaningful role and ongoing relationship with the resident and to establish constructive relationships with staff.

Carers Victoria submits that there is a need to support approved providers of both residential aged care and home care packages with a framework for working in partnership with family and friends.

Carers Victoria submits that delegated legislation such as the Aged Care Principles and Determinations must also be amended to ensure their compatibility with the Carer Recognition Act. Amendments are proposed to the User Rights Principles 1997 as follows:

In addition to the Charter of Residents Rights and Responsibilities and the Charter of Rights and Responsibilities for Community Care, there is a need to establish user rights principles for carers of people receiving residential and community aged care services under the Aged Care Act.

These would take the form of a Charter of Rights and Responsibilities for Relatives and Friends (Residential Aged Care) and a Charter of Rights and Responsibilities for Carers (Home Care Packages).

Carers Victoria submits that carers should have the right to complain and to take action to resolve disputes about their own treatment by the approved provider without fear of reprisal, without fear of losing services or being disadvantaged in any other way.

These rights and responsibilities would apply except where the resident explicitly refuses to give their consent or where there are legal barriers to such involvement.

The Act as it stands does not provide for sufficient recognition of the role of representatives of aged care recipients. There are inconsistent references to representatives contained in the Principles. For example, Section 18.4 of the Quality of Care Principles has a list of examples of representatives:

1. Advocate
2. Carer
3. Legal guardian
4. Relative

However, in Section 23.25 of the User Rights Principles, a representative of a person receiving community care is defined firstly as a person nominated by the recipient as someone they wish to participate in decisions relating to his or her care.

Due to the silence of the Act on who may be a representative, approved providers of residential aged care may turn to the Residential Care Manual 2009 for guidance. This advice suggests that a representative may be (in this order):

- A person appointed by a tribunal
- A person formally delegated with power of attorney by the resident
- A person nominated by the resident
- A person the approved provider is satisfied is connected to and concerned for the safety, health and wellbeing of the resident e.g. a family member or carer

This is problematic on a number of counts, primarily because of the emphasis on legally appointed representatives. This causes many difficulties for families where the aged care resident has not “put their affairs in order” prior to loss of capacity and in states and territories where tribunals are very reluctant to appoint a guardian unless there is no other alternative.

Carers Victoria submits that this guidance can also have the effect – in the absence of a legal arrangement, of a view by approved providers that they have the power to determine who can or cannot be a representative of a resident. We also hear from family carers that approved providers may choose to only have dealings with a family member who holds a financial power of attorney even in regard to lifestyle and day to day care decisions.

Carers Victoria recommends a consistent definition of representative that emphasises:

1. Firstly the role of the aged care recipient in nominating the person or persons whom they wish to participate in decision making about their care and;
2. Secondly the role of partners, carers and other relatives where the person is unable to do this.
3. Thirdly a person who holds enduring power of attorney (health/medical/lifestyle decisions)
4. Finally, a person appointed by a State or Territory guardianship board

Clear guidance is required on distinguishing between the decision making authority of those who hold the different types of Powers of Attorney and the nature of the decision to be made. For example, the approved provider may need to discuss fees and charges with one family member (who holds financial power of attorney) and day to day care arrangements with another – perhaps the person most involved with the recipient.

Carers Victoria further recommends that approved providers should be required to work with representatives unless they have cause to believe that the nominated representative is NOT acting in the best interests of the recipient.

These changes would ensure that the amendments to the Aged Care Act will not only be consistent with the principles of the Carer Recognition Act, but provide additional substance to the implementation of the priorities and actions contained in the National Carer Strategy.

Thank you for your time.



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