

Alzheimer's Australia submission on a draft National Patient Charter of Rights

Note: While our input focuses on issues for people with dementia and their families and carers, we believe that the issues that we highlight also apply to a wide range of other consumers.

Alzheimer's Australia supports the development of this National Charter. The current draft provides an excellent start however, we would like to raise the following concerns.

Partnership

We believe that consumers should be supported as full partners in the provision of health care. However, the Charter as written appears to be predicated on the assumption that individuals are physically and cognitively well enough to participate fully in this way. Health diversity is not recognised, eg disability is not acknowledged under the 'Respect' principle.

In addition, the role of family carers is not covered in the draft Charter and only in a peripheral manner in the Principles. Family carers provide much-needed and wide-ranging support to people with dementia within health settings. This is noted in the introduction to the Principles and under 'Information'.

Cognitive disability and ill health will impact on an individual's ability to 'meet the expectations' set out under the draft Principles. The very vital role that family and others commonly play should be appreciated and fully acknowledged.

These issues might be addressed by including:

- an additional right to 'support' in the Charter;
- a preamble which points to the partnership principle while acknowledging the limitations imposed by cognitive and other health issues. Such a preamble could also acknowledge the very real role that family members and carers play as support people and substitute decision makers;
- additional points related to these issues under the Principles, where appropriate.

Recognition of dementia

Alzheimer's Australia has just completed research for the Department of Health and Ageing into the viability and potential impact of developing a National (and International) dementia symbol within the Acute, Community, Residential and Transitional care settings; emergency services and the broader community.

The concept of a symbol for people with dementia was an outcome of the October 2005 National Consumer Summit on Dementia. Participants suggested that people with dementia and their family carers required a National symbol in order to encourage appropriate treatment of people with dementia, particularly in relation to the delivery of care services. They also called for action to 'Improve the responsiveness of acute care so it better meets the needs of people with dementia'.¹

¹ <http://www.alzheimers.org.au/upload/Communique2.pdf>

In order to exercise their rights under this type of patient charter, consumers need health staff to:

- be able to recognise possible or probable dementia or other forms of cognitive impairment where this has not been diagnosed;
- understand the implications of dementia, delirium, etc on care delivery and their professional practice;
- provide best practice support to the people with cognitive impairment who use their services.

This implies that:

- consumer records, including information about diagnosis and cognitive deficits, are available to staff;
- every member of the care staff has the necessary knowledge and understanding of dementia to communicate appropriately, manage pain, etc;
- management takes into account the impact of cognitive deficits in how health facilities are run and services delivered

Without leadership and training to underpin rights and principles, people with dementia will not receive the care that they should, and safety will inevitably be compromised. More information is available on Quality Dementia Care at <http://www.alzheimers.org.au/content.cfm?topicid=351>

Advance planning

There should be recognition under 'Respect' that consumers have views about the health care that they want and do not want. Respecting advance planning arrangements supports people with dementia and their family carers in achieving the health outcomes that the individual may have planned and respects his or her wishes.

Implementation

While the Charter generally provides a useful tool to 'support safe and high quality care', the approach to implementation will be very critical.

Alzheimer's Australia is well-positioned and willing to provide further information or other assistance to help the Commission to address implementation issues around dementia or cognition more generally.

Further comment

Studies have indicated that:

- the number of people with dementia is projected to increase from about 227,000 in 2008 to 731,000 in 2050;
- the prevalence of dementia doubles with each 5 year increase in age after 65, until about 1 in 4 have dementia at ages over 85;
- life expectancy is shortened after a diagnosis of dementia, although it is not known the differential impact of disease progression, reduction in ability to manage co-morbidities or decreased access to the range of health options;
- People with dementia who are unable to request pain relief for conditions such as hip fracture, receive less pain medication than those without a diagnosis.