Submission template

Aged Care Legislated Review

Submissions close 5pm, 4 December 2016

Instructions:

- Save a copy of this template to your computer.
- Populate Section 1 with your details.
- If you would like to respond to a specific criteria please use Section 2 of the template.
- If you would like to provide general comments please use Section 3 of the template.
- Upload your completed submission on the Consultation Hub. Alternatively, if you are experiencing difficulties uploading, you can email your submission to agedcarelegislatedreview@health.gov.au

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Thank you for your interest.

1. Tell us about you

1.1 What is your full name?

First name Liz

Last name Callaghan

1.2 What stakeholder category do you **most i**dentify with?

Peak body - consumer

1.3 Are you providing a submission as an individual (go to question 1.4) or on behalf of an organisation (go to question 1.5)?

Organisation

1.4 Do you identify with any special needs groups?

Choose an item.

1.5 What is your organisation's name?

Palliative Care Australia

1.6 Which category does your organisation **most** identify with?

Consumer Peak Body

1.7 Do we have your permission to publish parts of your response that are not personally identifiable?

☒Yes, publish all parts of my response except my name and email address

☐No, do not publish any part of my response

2. Response to Criteria in the Legislation

2.1 Whether unmet demand for residential and home care places has been reduced

Refer to Section 4(2)(a) in the Act

In this context, unmet demand means:

- a person who needs aged care services is unable to access the service they are eligible for e.g. a person with an Aged Care Assessment Team / Service (ACAT or ACAS) approval for residential care is unable to find an available place; or
- a person who needs home care services is able to access care, but not the level of care they need e.g. the person is eligible for a level 4 package but can only access a level 2 package.

There are many cases where a person has a hospital admission for an acute issue such as a fall or infection, and it is determined during that admission that they are no longer independent enough to go home. During the time waiting for the ACAT assessment and seeking a suitable residential aged care service, the person remains in hospital and the cost of their hospital stay escalates. Further, the patient and family may feel pressured to choose the earliest available place, rather than the place that best suits their needs. This problem has not been resolved through the introduction of the legislation.

Case study 1 Unmanaged severe pain

A daughter phoned Palliative Care Victoria (PCV) regarding her 94-year-old Mum, who was living independently until recently when she was admitted to hospital for investigation of severe stomach pain. Investigations did not identify the source. Subsequently, she was admitted to a Residential Aged Care Facility (RACF) for respite and she remains there. However, she continues to have periods of severe stomach pain. She did have a fentanyl patch to relieve the pain, but the facility doctor removed it suspecting constipation was the source of pain. The daughter is very concerned as mother still has periods of severe, uncontrolled pain and she is not at all happy with GP. The daughter asked RACF about palliative care, but they feel this is beyond their abilities. It should be noted that the daughter feels that the RACF staff are very caring.

2.2 Whether the number and mix of places for residential care and home care should continue to be controlled

Refer to Section 4(2)(b) in the Act

In this context:

- the number and mix of packages and places refers to the number and location of residential aged care places and the number and level of home care packages allocated by Government ; and
- controlled means the process by which the government sets the number of residential care places or home care packages available.

No comment

2.3 Whether further steps could be taken to change key aged care services from a supply driven model to a consumer demand driven model

Refer to Section 4(2)(c) in the Act

In this context:

- a supply driven model refers to the current system where the government controls the number, funding level and location of residential aged care places and the number and level of home care packages;
- a consumer demand driven model refers to a model where once a consumer is assessed as needing care, they will receive appropriate funding, and can choose services from a provider of their choice and also choose how, where and what services will be delivered.

Consumers need to be better supported to make decisions about the services offered by aged care homes. On the 'My Aged Care' website on the page about end of life care, it suggests that the resident agreement should outline whether or not the home will be able to provide care at the final stages of life. However, this is not specifically identified as a component of the Residential Agreement on the page about Agreements with your Aged Care Home. PCA would advocate this change to ensure that the availability of end of life care is clearly identified for consumers within the residential agreement.

Additionally, there is an unwillingness in the community to openly acknowledge that most people in residential care will be there until the end of their life. Legislation and policy are also silent on this matter. Consequently, when choosing a service the potential palliative care needs of the resident may not be given sufficient attention. More information and support around this issue could ensure that palliative care is more easily factored into the decision making process of consumers.

The same is true for consumers supported through home care packages. While many services promote their service as offering palliative care there needs to be greater detail provided to consumers as to what that care would constitute.

2.4 The effectiveness of means testing arrangements for aged care services, including an assessment of the alignment of charges across residential care and home care services

Refer to Section 4(2)(d) in the Act

In this context:

- means testing arrangements means the assessment process where:
  - the capacity of a person to contribute to their care or accommodation is assessed (their assessable income and assets are determined); and
  - the contribution that they should make to their care or accommodation is decided (their means or income tested care fee, and any accommodation payment or contribution is determined).

No comment

2.5 The effectiveness of arrangements for regulating prices for aged care accommodation

Refer to Section 4(2)(e) in the Act

In this context:

- regulating prices for aged care accommodation means the legislation that controls how a residential aged care provider advertises their accommodation prices.

No comment

2.6 The effectiveness of arrangements for protecting equity of access to aged care services for different population groups

Refer to Section 4(2)(f) in the Act

In this context equity of access means that regardless of cultural or linguistic background, sexuality, life circumstance or location, consumers can access the care and support they need.

In this context different population groups could include:

- people from Aboriginal and/or Torres Strait Islander communities;
- people from culturally and linguistically diverse (CALD) backgrounds;
- people who live in rural or remote areas;
- people who are financially or socially disadvantaged;
- people who are veterans of the Australian Defence Force or an allied defence force including the spouse, widow or widower of a veteran;
- people who are homeless, or at risk of becoming homeless;
- people who are care leavers (which includes Forgotten Australians, Former Child Migrants and Stolen Generations);
- parents separated from their children by forced adoption or removal; and / or
- people from lesbian, gay, bisexual, trans/transgender and intersex (LGBTI) communities.

PCA and its members have concerns about ongoing issues with My Aged Care and its effective functioning for CALD clients.

Example 1 A CALD client with poor English and knowledge of the service system may ask their CALD community organisation to assist them with the My Aged Care process. A call-back message may be left with My Aged Care but rather than call the CALD community organisation, My Aged Care contacts the client directly. Consequently, the CALD client receives much more limited support than the CALD community organisation knows they need and could access. The CALD community organisation then has to spend a lot of unfunded time advocating on behalf of the CALD client with My Aged Care in order to get a more appropriate service response for the client.

Example 2 If My Aged Care calls back twice and there is no response by the client – who may have asked the CALD community organisation to manage the process for them – then the client's request goes to the back of the queue and it can take months to get the help they need. In the meantime the CALD community organisation has to find other ways to assist.

In addition PCA member organisations and PCA are **continually** being rung by consumers who have been told whilst on the phone to My Aged Care, that they can access equipment or services, such as respite, through PCA or its member organisations. PCA and its member organisations are peak bodies not service providers. This causes great distress for families who do ring PCA and our members, as we have to tell the consumer that they need to phone My Aged Care again and begin their conversations all over again. This issue has been raised with Department of Health aged care staff twice in the past, but remains a significant issue.

2.7 The effectiveness of workforce strategies in aged care services, including strategies for the education, recruitment, retention and funding of aged care workers

Refer to Section 4(2)(g) in the Act

In this context aged care workers could include:

- paid direct-care workers including: nurses personal care or community care workers; and allied health professionals such as physiotherapists and occupational therapists; and
- paid non-direct care workers including: managers who work in administration or ancillary workers who provide catering, cleaning, laundry maintenance and gardening.

The aged care workforce is now caring for people with long-term, sub-acute, complex chronic health conditions. Research demonstrates the benefit of providing palliative care to patients with many of these conditions and also suggests considerable savings can be made by preventing hospital admissions (1,2,3). Within residential aged care, at least, it appears that the staffing skill mix and numbers are no longer adequate to deliver high quality holistic care thus preventing them from dying in the facility. More often they are transferred to a hospital while actively dying.

Education strategies that have been put in place include education provided by the Decision Assist program to aged care workers and general practice, and access to specialist advice on palliative care and advance care planning through a dedicated phone line. Uptake of the education sessions and phone line use has been poor, with RACFs not supporting the use of the telephone lines (averaging less than 30 calls per month nationally of the specialist palliative care phone line and around 10 calls or less per month of the advance care planning phone line). A very small percentage of GPs have taken up the offer for continuing professional education, and the reach of aged care workshops has also been poor nationally.

Case studies received from PCA member organisations demonstrate at times an inability for some services to provide palliative care at the end of life, particularly if the person dying has complex symptoms.

Case study 2 Insufficient RACF staff to address needs of palliative patients
A caller to one of our member organisations was concerned that residential aged care staff were too stretched to provide the care that was needed. The caller felt that access to palliative care consultancy for aged care staff inadequate to address the need for day to day care support. Therefore, the caller inquired about purchasing private palliative care services.

Case study 3 Insufficiently skilled staff to address needs of palliative patients
An Indian woman rang about her husband who is in a large residential aged care facility and is actively dying from kidney failure. A community palliative care service has supported the facility to manage his care. His wife says the facility has very few staff, and no RNs on duty overnight so she has been staying with him overnight for the past 10 days. She is now exhausted and cannot continue to do this. She inquired whether a community palliative care service would be likely to provide an overnight nurse for him at the aged care facility until he dies. Her husband does not have a regular GP and has been seen by the RACF visiting GP. They have not seen or spoken to the oncologist since he stopped having active treatment.

For further commentary, see the full PCA submission to the aged care workforce inquiry.

1 Davis, Mellar P et al. “A Review of the Trials Which Examine Early Integration of Outpatient and Home Palliative Care for Patients with Serious Illnesses.” 4.3 (2015): 99–121.
2 Smith, Thomas J et al. “JOURNAL OF CLINICAL ONCOLOGY American Society of Clinical Oncology Provisional Clinical Opinion : The Integration of Palliative Care Into Standard Oncology Care.” 30.8 (2012): 880–887.
3 Gardiner, Clare et al. “What Cost Components Are Relevant for Economic Evaluations of Palliative Care, and What Approaches Are Used to Measure These Costs? A Systematic Review.” Palliative Medicine (2016)

2.8 The effectiveness of arrangements for protecting refundable deposits and accommodation bonds

Refer to Section 4(2)(h) in the Act

In this context:

- arrangements for protecting refundable deposits and accommodation bonds means the operation of the Aged Care Accommodation Bond Guarantee Scheme .

No comment

2.9 The effectiveness of arrangements for facilitating access to aged care services

Refer to Section 4(2)(i) in the Act

In this context access to aged care services means:

- how aged care information is accessed; and
- how consumers access aged care services through the aged care assessment process .

There are funding provisions in place to support delivery of palliative care services to people both in hospitals and in the community. These include various programs implemented by state/territory governments as well as provisions in the Medicare Benefits Schedule for providing home visits and case conferencing to people living in the community that require access to palliative care. No such funding is available for residential care. This suggests that older people in residential services may not have the same access to palliative care.

The ACFI does not provide a funding mechanism for the important work of aged care staff (clinicians) in facilitating advance care planning (ACP) and or case conferencing at the end of life. This has been highlighted significantly in the work of the Commonwealth funded Decision Assist Project that recognises the importance of a multidisciplinary focus in building a palliative care program that meets the needs of the care recipient, their family and the staff that deliver care and services. Older Australians residing in Residential Aged Care Facilities should be provided equity of access to specialist palliative care if needed, in the same way that those services are available to other Australians.

As mentioned previously, PCA member organisations and PCA are continually being rung by consumers who have been told whilst on the phone to My Aged Care, that they can access equipment or services, such as respite, through PCA or its member organisations. PCA and its member organisations are peak bodies not service providers. This causes great distress for families who do ring PCA and our members, as we have to tell the consumer that they need to phone My Aged Care again and begin their conversations all over again. This issue has been raised with Department of Health aged care staff twice in the past, but remains a significant issue, and demonstrates that the ineffectiveness of accessing information about aged care through the My Aged Care website.

3. Other comments

No comment