

Submission template

Increasing Choice in Home Care – Stage 1

Proposed changes to Aged Care Principles and Determinations

Submissions close 5pm, 9 June 2016

Please note that the Government has entered a caretaker period. Policy decisions that bind a future Government will not be made during this period. However, the Department is proceeding to consult during this period so that if the incoming Government agrees to the proposed approach, implementation can occur as soon as possible.

Instructions:

- Save a copy of this template to your computer.
- You do not need to respond to all of the questions.
- It is recommended that you read the relevant pages in the consultation paper prior to responding.
- Please keep your answers concise and relevant to the topic being addressed.
- Upload completed submission on the [Consultation Hub](#). Alternatively, if you are experiencing difficulties uploading, you can email your submission to: agedcarereformenquiries@health.gov.au

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Thank you for your interest in participating in our consultation.

1. Tell us about you

What is your full name?

First name **Carol**

Last name **Bennett**

What is your organisation's name (if applicable)?

Alzheimer's Australia

*What stakeholder category do you **most** identify with?*

Peak body - consumer

Where does your organisation operate (if applicable)? Otherwise, where do you live?

All states and territories

What is your email address?

Carol.bennett@alzheimers.org.au

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

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

2. Prioritised Home Care Recipients Principles 2016

National prioritisation process

Do you think that any other variable should be considered in the national prioritisation process? In addition to relative needs and time waited.

Refer to pages 9 – 11 of the consultation paper

Consumers with degenerative conditions, such as dementia, can be expected to have high and increasing care needs over time. The national prioritisation process needs to take this into account. As needs will not be static, there should be an ability to move seamlessly to higher care packages as required.

Do you think that the application of Item 5 is equitable?

Refer to pages 9 – 11 of the consultation paper

The inclusion of Item 5 would appear to mean that consumers with degenerative conditions, such as dementia, will need to enter a new queue for an increased care package each time their level of need increases. Depending on the length of the queue, the person with dementia and their carer may need to wait some time to access the required level of care, which is likely to place increased strain on the person and their carer. One objective of the system should be to support people with dementia to live at home for as long as possible, as this is the preference of most people with dementia and their family members, and is also more cost-effective for the aged care and health systems. We know that 70% of people with dementia currently live in the community, and over 90% of these people do so with the support of an informal/family carer. These carers often experience multiple negative impacts – psychological, physical and financial – and delays in access to the formal care and support which the person requires can only compound this situation. Supporting the sustainability of the caring arrangements which allow people with dementia to live in the community for as long as possible must be a priority. Where it is known at the outset that a person’s condition will inevitably deteriorate over time, as is the case for a person with dementia, measures must be in place to ensure seamless and speedy progression through care package levels as the person’s needs increase. To underpin this, better assessment of cognitive impairment is needed in the aged care assessment process.

Cessation of prioritisation determinations

Is a 56 day period to activate a package appropriate?

Refer to pages 11 – 12 of the consultation paper

Yes, provided that as outlined in the consultation paper, My Aged Care seeks to contact and understand why the person has not taken up care before the notice ceases and determine if an extension is required. People with dementia and their carers may experience difficulty negotiating and activating a package due to the very nature of dementia, and all efforts must be made to facilitate access to care rather than taking a punitive approach. Removal of eligibility for a package should only occur where there is a clear rationale for taking such action.

Is the option to extend the period by 28 days required? Is this an appropriate period of time?

Refer to pages 11 – 12 of the consultation paper

Yes, with the caveats outlined above.

Should a consumer's package automatically cease when they permanently enter residential care?

Refer to pages 11 – 12 of the consultation paper

For consumers with dementia who enter residential care, access to specialised non-clinical support, such as cognitive support/social support, should continue.

3. Aged Care Legislation Amendment (Increasing Consumer Choice) Principles 2016

3.1. Accountability Principles 2014

Is a 31 day timeframe for provision of the cessation date appropriate? Or should a shorter timeframe be proposed i.e. 14 days?

Refer to pages 13 – 14 of the consultation paper

Providers will have more insight into the time required to provide notice of the cessation date of a package. The main issue from the consumer point of view, is that moving between providers should be a simple and seamless process, and any failure by a provider to meet requirements such as providing a cessation date within a certain timeframe should not impede the consumer's access to care from another provider.

3.2. Allocation Principles 2014

Is there anything else that the Department should consider in the management of the cessation of home care places in the lead up to 27 February 2017?

Refer to page 15 of the consultation paper

Click here to enter text.

3.3. Approval of Care Recipients Principles 2014

Do you have any comments in relation to approval being at a specific level?

Refer to page 16 of the consultation paper

Classifications should be clear with regard to assessing the level of cognitive impairment of the care recipient, and align with services and supports appropriate to that level of cognition. Definitions should also be clear with regard to support for quality of life and independence measures.

3.4. Approved Provider Principles 2014

Are there any other matters that you think should be considered in the approval process for providers?

Refer to pages 18 – 19 of the consultation paper

Care for people with dementia is a core responsibility of all providers, and there must be clear criteria and expectations to support this. For example, all providers should be required to demonstrate that their staff are appropriately educated and trained in dementia care, and that this is maintained over time.

3.5. Quality Agency Principles

Do you have any comments in relation to the proposed changes to the Quality Agency Principles?

Refer to page 20 of the consultation paper

The Australian Aged Care Quality Agency will need to match the pace and scale of the reforms that are being implemented. We are encouraged to note that the Department will be working with stakeholders to develop a single streamlined national quality framework for all aged care services and that quality reviews will continue for home care providers who are providing services to consumers. However, we are concerned that these important quality mechanisms may not be developed in time to match the implementation of the proposed changes. It is paramount that these are developed and implemented in tandem with the changes in February 2017. Additionally, to ensure that CDC objectives can be integrated into quality and compliance processes, consumers should be engaged as key partners in these processes. Consumers welcome a more central role in the quality monitoring process. The development of quality indicators for home care standards is a welcome move. Measures of quality in home care should be based around the provision of holistic care, in conjunction with other services, to enable people living with dementia to remain at home for as long as is feasible, if this is the person's preference. This must include services such as support for carers, support for social engagement including volunteering, and access to flexible respite care including overnight care. To deliver quality care, services must have adequate numbers of skilled, qualified staff, committed to providing person-centred care. Staff must be educated and trained in key aspects of care, including person-centred care and caring for people with dementia. Consumers, carers, and appropriate volunteers should be engaged as key partners in quality and compliance processes. Consumer satisfaction with home care services should be monitored, including through surveys administered by AACQA. Quality reviewers for home care services should conduct interviews with at least 10% of services users and/or representatives during the site visit, in line with the process for residential aged care. Quality standards should be continually strengthened to drive continuous improvement, and quality of life measures need to be addressed in this context. Reporting of outcomes against quality indicators is also vital.

3.6. User Rights Principles 2014

Transparency and disclosure of exit fees

For consumers, do the proposed provisions provide adequate transparency and disclosure of exit fees?
Refer to pages 22 – 23 of the consultation paper

With regard to exit fees, and indeed all fees in relation to home care, measures must be in place to ensure consumers are fully informed and protected, to prevent financial abuse. Consumers have raised concerns about the lack of transparency with regard to brokerage fees and other financial arrangements. People with dementia and their carers are particularly vulnerable to financial abuse, due to the very nature of dementia, and must be protected. Alzheimer’s Australia proposes that in addition to measures to require full disclosure of exit fees, the Commonwealth should place an absolute cap on the exit fee able to be charged by a provider (such that any published exit fee or agreement exit fee must be equal to or below this absolute cap). The maximum allowable exit fee under this capping arrangement should simply be sufficient to cover the administrative requirements of ending or transferring a package. Providers should not profit unduly through the exit of a consumer from their service, as this may create a perverse incentive for providers to “move consumers on” – particularly those who are most vulnerable and may be more challenging to provide a service to, including people with dementia. High exit fees may also discourage consumers from moving to another service provider, even if they are dissatisfied with the care received, thereby undermining the first principles of consumer-directed care. The User Rights Principles should also include a provision that service providers cannot withhold or reduce services to a client once they have decided to change provider (thereby ensuring the exit fee reaches the maximum amount for the provider). This point is made with reference to the scenario where the unspent home care amount is less than the exit fee that the provider has published, which results in the provider receiving a lesser fee than they would have anticipated. Guidelines relating to this type of scenario would prevent the client receiving less service hours before the client moves to another provider. Note also that exit fees are not the only area of concern. Alzheimer’s Australia has received reports from consumers of Commonwealth Home Care Package providers increasing their administration fees in response to the CDC changes, and charging up to 70% of packages on administration fees, in some cases leaving very little funding for actual care; and consumers have raised concerns that there is very little transparency with regard to these fees. It is imperative that in regard to administration fees there is also adequate transparency and disclosure, including publication of the fees on My Aged Care; and Alzheimer’s Australia also proposes that an absolute cap be in place in relation to the quantum of administration fees that can be charged by providers. While comparative information about administration/management fees is helpful, in areas where there is no competition, such as some rural and remote areas, consumers are not in a position to choose a provider that charges a more reasonable fee. If rural and remote providers have higher costs, this should be dealt with in the funding formula rather than through the deduction of high management fees which impact on the funds available for service delivery. While mandating a maximum fee may encourage service providers to charge that fee, this would still be an improvement on the current situation.

For providers, will the proposed provisions assist to cover administration costs associated with reconciling unspent home care amounts and finalising home care packages?

Refer to pages 22 – 23 of the consultation paper

Click here to enter text.

Reconciliation and payment of unspent home care amounts

Are the proposed timeframes for approved providers to manage unspent home care amounts reasonable and appropriate?

Refer to pages 24 – 27 of the consultation paper

Click here to enter text.

For providers, are the proposed timeframes sufficient to accurately reconcile package funds (within 56 days of the cessation day) and arrange payment (within 70 days of the cessation day)?

Refer to pages 24 – 27 of the consultation paper

Click here to enter text.

For consumers, are the timeframes appropriate, particularly where the consumer wishes to utilise the funds as soon as possible with another home care provider?

Refer to pages 24 – 27 of the consultation paper

We note that when a consumer wishes to change providers, if the outgoing provider is notified within 56 days that the consumer has entered into an agreement with a new provider, the outgoing provider must transfer the unspent home care amount within 70 days after the cessation date. If there is a significant sum of unspent funds and the consumer wishes to utilise the funds as soon as possible with a new provider, it is unclear that this 10-week timeframe for transfer of funds will allow the consumer to move seamlessly to the new provider and access all necessary services immediately. It is also of concern that the sanctions proposed where providers fail to transfer funds within the required timeframe are very weak (see comments below). Any “service gap” resulting from a delay in transfer of funds would represent another disincentive for consumers to change service providers, again undermining the first principles of consumer-directed care.

Consequential amendments

Do you have any comments in relation to these amendments?

Refer to page 27 of the consultation paper

Click here to enter text.

3.7. Sanctions Principles 2014

Do you support or have any concerns about the proposed sanction?

Refer to page 30 of the consultation paper

Alzheimer's Australia notes that it is proposed that a new sanction be included in the Sanctions Principles to the effect that if a home care provider is non-compliant with its responsibilities to make payment of an unspent home care amount under the User Rights Principles, that is, fails to pay all or part of a care recipient's unspent home care amount to the relevant party, the proposed sanction would require the provider to make the payment within the period specified in the sanctions notice. We are concerned that this sanction is too weak: it is simply a requirement to eventually transfer the funds, with no penalty for delay. It appears that a provider will be able to delay transferring potentially significant sums of unspent funds with no penalty in place for non-compliance. Given that there is a perverse financial incentive for a provider to hold onto unspent funds for as long as possible, financial penalties in the form of appropriate fines should be in place and enforced, to remove this incentive and ensure such delays do not eventuate. Delays in funds transfers may impede access by consumers to home care services from another provider, and could act as a disincentive to change providers, thereby undermining the first principles of consumer-directed care.

3.8. Records Principles 2014

Are there any other records that should be kept and retained by an approved provider?

Refer to page 31 of the consultation paper

Alzheimer's Australia supports the new provisions requiring providers to keep copies of notices relating to unspent home care amounts, and records relating to the payment of unspent home care amounts to the estates of care recipients, other approved providers, and care recipients.

4. Aged Care (Subsidy, Fees and Payments) Determination 2014 and Aged Care (Transitional Provisions) (Subsidy and Other Measures) Determination 2014

Do you have any comments in relation to the amendments to the determinations?

Refer to page 32 of the consultation paper

Click here to enter text.

5. Other comments

Do you have any general comments or feedback on other issues relating to the proposed changes?

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia poses a unique challenge for Australia due to increasing prevalence, economic costs and social implications. Changes in community expectations are also creating greater demand for community based, consumer-driven models of support and a broader range of specialist services. Dementia is the second leading cause of death in Australia and will have an increasing impact on the health system due to population ageing. Dementia will become the third greatest source of health and residential aged care spending within two decades. These costs alone will be around 1% of GDP¹. Estimates by AIHW indicate that 30% of people with dementia lived in residential care in 2011, while 70% lived in the community.²

Provision of comprehensive community based support is critical to meet the needs of people living with dementia. Alzheimer's Australia supports the Government's commitment to aged care reform and the ongoing implementation of Consumer Directed Care (CDC) across the aged care system. We support the broader intent of CDC and recognise its aim to provide consumers with greater control over their own health and wellbeing by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when. However, we remain concerned about the current inability of mainstream services to deliver appropriate services for people with dementia. Specialist services such as dementia specific advocacy, information and support are critical.

To achieve a quality home care system under the new CDC model, it is vital that we have informed and engaged consumers, well supported in decision-making. For people with dementia, as for those people without dementia, having a say in their everyday lives is a basic desire and underpins a sense of purpose and well-being. Many people with dementia have expressed a desire to feel that they are participating in decision making regarding their care but also recognise that their ability to do so is, and will be, compromised by the very nature of dementia. Consumers have identified the need for greater transparency across the implementation of CDC reforms. A central principle of CDC should be to ensure that the entire interactive communication process supports consumers to fully understand the proposed care plan and the choices available to them, and provides the information necessary to support informed decision-making.

Consumers attending an Australian Government Consumer Focus Group with Alzheimer's Australia in March 2016, to discuss the Increasing Choice in Home Care proposals, suggested providing easy to access information for consumers on the roles and responsibilities of home care providers, to help improve their understanding of how services are to be delivered. Specific suggestions included a resource toolkit for consumers, including information on the rights of consumers and the responsibilities of providers; consumer checklists for entering into a home care agreement; information about the Aged Care Complaints Commissioner; information on co-contribution and payments for aged care services; as well as information to support consumers to compare and choose between providers. Key information consumers identified that they need in the context of the Service Finder included: case management information (what consumers can expect for this service); fees and charges; service availability; hours of operation; the education and qualifications of staff; the provider's complaints process; and provision of specialised services (eg for CALD, LGBTI, Aboriginal and Torres Strait Islander clients). Participants also identified the need to enhance the accessibility of

¹ Australian Institute of Health and Welfare (2012). Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW.

² Op. Cit AIHW 2012.

the My Aged Care website. Alzheimer's Australia has previously highlighted some of the issues being experienced by people with dementia and their families and carers in using My Aged Care. A key factor appears to be the need for better support and training for contact centre staff to enable them to respond to the information needs of people with dementia, carers and families. This is concerning, not only because people with dementia are high users of aged care services, but also because carers of people with dementia often experience significant negative impacts, such as stress and depression. People with dementia and their families and carers will experience unique challenges when participating in CDC programs due to complex symptoms and the progressive decline in cognitive functioning that are the hallmarks of dementia. The issues raised by consumers as CDC has begun rolling out, highlight the complexities in balancing the needs of clients, service providers and governments, while ensuring timely access to essential services within a robust framework of consumer protections. This highlights the need for an increased and more robust focus on the quality of care provided in the community to ensure standards of care are maintained and continually improved.

The Case Manager's role has been highlighted by consumers in their input to Alzheimer's Australia, as a key factor in the success or otherwise of home care packages. Providers need to be mindful of the significance of this role and make appropriately experienced and qualified appointments to these positions.

A comprehensive aged care advocacy framework is a critical element to support the implementation of CDC. The scale of reform across aged care is significant, and it is vital to ensure that consumers are supported, empowered and have their rights protected during this period of change and within an evolving aged care system. Genuine consumer directed care for people with dementia can be delivered only when consumers are enabled and supported as partners in the decision-making process. A robust advocacy framework is a good starting point in ensuring that consumers have access to advocacy that supports their needs and requirements.

Alzheimer's Australia remains positive about achieving greater consumer choice and flexible services under CDC. For people with dementia and their families and carers, these objectives are particularly important given the progressive nature of the condition which requires responsive individually tailored solutions from service providers that will evolve over time and with the individual's condition. It is important to emphasise that these goals will only be achieved for people with dementia if their specialised needs are recognised and supported.

Thank you for the opportunity to comment.