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The new voice of Alzheimer's Australia

Draft Charter of Aged Care Rights

Submission from Dementia Australia

October 2018

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 436,000 Australians living with dementia and the estimated 1.4 million Australians involved in their care.

Dementia Australia works with consumers, all governments, and other key stakeholders to ensure that people with dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with consumers means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

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EXECUTIVE SUMMARY

Dementia Australia welcomes the opportunity to provide input on the Department of Health's Consultation on the draft Charter of Aged Care Rights.

Dementia Australia acknowledges the move towards a single set of compliance and statutory statements across Commonwealth subsidised aged care areas, however, in the pursuit of universality and efficiencies, it is imperative that the needs and preferences of people living with dementia are represented.

Overall, we welcome the approach in principle towards a single draft Charter of Rights to replace the multiple current charters which cover residential, home care, short term restorative services both in residential and home care services. Dementia Australia is concerned that the current draft Charter does not adequately reflect the rights of people living with dementia who are dependent on their carers, support networks and advocates to ensure that they are receiving quality care which is safe and suitable for their needs. In short, our position is that these Rights need to be inclusive of carers and advocates and specifically articulate their positions.

For people living with dementia, their families and carers, the Charter of Aged Care Rights is particularly important given the progressive and terminal nature of the condition which requires responsive and individually tailored solutions from service providers that will evolve over time to remain aligned with the individual's situation. It is important to emphasise that these goals will only be achieved for people with dementia if their specialised needs are recognised and supported. It is therefore imperative that the Rights reflect these specialised needs.

Dementia Australia urges the Department to consider and include issues relating to the safety and quality of care for people with dementia and reflect them in the Charter. As the prevalence of dementia increases in our community, it is critical that all considerations of quality in aged care, including the Charter of Rights, be fully inclusive of issues relating to dementia.

More than 50% of people in Residential Aged Care have a diagnosis of dementia, many more residents are undiagnosed and more again will develop dementia whilst they are in care. One in three people over the age of eighty-five will develop dementia.

Draft Charter of Aged Care Rights

Charter of Consumer Rights

I have the right to:

a) receive safe and high-quality care and services
All consumers have the right to receive safe and high-quality care and services. Providers need to understand and respond appropriately to consumers' needs; ensure consumers understand the care and services they are to receive; and ensure staff are well supported with education and resources to deliver these services.

b) be treated with dignity and respect and to have my individuality valued

Being treated with dignity and respect means recognising consumers' strengths and empowering them to maintain their independence, and communicating respectfully. It also means understanding the life that the consumer has lived, the life they want to live and who they are, and having the consumers' best interests at heart, while being respectful of their personal choices.

c) have my identity, culture and diversity valued and supported
Respect is valued and shown for consumers' beliefs, values, personal characteristics, culture and diversity.

d) maintain my independence
Consumers are supported to explore additional services (including technology) that can allow them to continue to have a meaningful life and be independent as they age. Consumers are also supported to participate in ongoing assessment and planning, and to continue to make decisions about, their own care and services.

e) live without abuse and neglect
The provider's workforce is kind and caring and respectful of each consumer such that consumers feel emotionally and physically safe and secure in their care environment.

f) be informed about my care in a way that meets my needs, have access to information about my rights, care, accommodation and anything else that relates to me personally, and get the information I need in a timely way
Consumers receive open, relevant and timely information about their care and services. Providers ensure consumers understand the information provided to them. Providers need to be alert to signs of confusion or misunderstanding. Information should be provided in a format that the consumer understands. This may require making arrangements to meet language or communication needs.

g) maintain control over, and continue to make decisions about, my care and personal and social life
Consumers are supported to maintain control and make decisions, including to: take risks to live the best life they can; choose who to have relationships with; enjoy social engagements outside the service; and express their views in matters affecting them. Consumers can say no or change their mind at any time.

h) be listened to and understood
Taking the time to listen to, understand and acknowledge what the consumer is saying helps consumers to feel heard. This may require different methods of communication to be used.

i) choose to have another person speak on my behalf
Consumers can choose someone else, or a number of different people to speak on their behalf and represent their interests, especially in formal situations or when the consumer doesn't feel confident or able to speak up.

j) complain, and to have my complaints dealt with fairly and promptly
Consumers should be able to provide feedback on or complain about their care and services without retribution. Consumers should be supported to articulate their concerns as feedback

and complaints can help improve services. Consumers should be informed about different options for raising concerns if they are not comfortable doing so with the provider. Providers need to respond to concerns attentively and efficiently.

k) exercise my rights without it adversely affecting the way I am treated
Consumers feel supported to use their rights, and raise issues about their rights freely without judgement, disapproval, criticism, being taken advantage of, or pressured.

l) personal privacy and to have my personal information kept confidential
Personal and health information is kept secret and hard copy documents are securely stored. The workforce shows respect for consumers and does not discuss consumers in front of others without permission of the consumer.

Response to Specific Consultation Items

1. Does the Charter cover what you think is important?

For people living with dementia the Charter does not sufficiently reflect their changing needs, preferences and dependence on support networks, including families, carers and advocates.

As such, the Charter is deficient in several areas.

- Lacking in detail, particularly when considering the comprehensive information contained within the current four Charters.

- Does not address the rights of people who require high level support or who may experience the need for future high level support, particularly those living with a decline in cognitive function or who are living with dementia.

- Does not refer to the supporting roles which are present and necessary in many elderly peoples' lives.

- Does not specifically articulate the principles of consumer directed care; User Rights Amendment (Consumer Directed Care) Principles 2015 for services received from Home Care Packages.

2. Does the introduction/preamble require clarification or any further information?

Preamble: The Australian Charter of Aged Care Rights (the Charter) helps to create a shared understanding about the rights of people receiving Commonwealth subsidised aged care. Having a shared understanding between people receiving care, their family, friends and carers, and aged care providers and their staff, helps everyone work together to achieve safe and high quality aged care. The rights described in this Charter sit alongside other laws that inform the delivery and quality of aged care, for example the broader Aged Care Act 1997, the consumer outcomes in the new Aged Care Quality Standards, and rights under the Australian Consumer Law and anti-discrimination law. The Charter helps people receiving care *understand how their aged care provider will work with them. It also helps people receiving care understand how they will engage with others involved in their aged care service – so that they can enjoy the same rights. Sometimes aged care providers may have to balance competing rights. Providers will work to resolve these situations sensitively through consultation and with the spirit of the Charter in mind.*

Dementia Australia considers that the preamble sets an ambiguous tone in regards to the role of the provider, by not clearly articulating the expectations of the provider, as seen in the statement below;

'Sometimes aged care providers may have to balance competing rights. Providers will work to resolve these situations through consultation and with the spirit of the Charter in mind'.

This statement is considered to effectively exonerate providers of their accountability towards the provision of care. If 'competing rights' are predicted to be an issue then it would be in the best interest of the Department to continue with the separate charters, particularly when the models of care are different. Within the current separate rights there are clear expectations articulated of each of the aged care programs.

It must be stressed that in the current political environment with the quality of aged care at the fore of public discourse and deliberation, the rights of the aged care consumer must be strongly supported with clear and robust guidelines.

Whilst it is stated in the draft preamble that the Charter will sit alongside the;

- Broader Aged Care Act 1997
- Consumer outcomes in the single quality standards
- Rights under the Australian Consumer Law and anti-discrimination law

The relevance of this Charter is distilled by this statement. It becomes unclear and is considered to add a layer of complexity by effectively needing to consult various laws and consumer outcomes. Not all consumers of aged care are able to understand the complex legal framework which surrounds consumer rights and responsibilities in aged care. Many people access aged care services and supports during a time of crisis in their lives and do not have ample time to scope all of the laws and regulations surrounding the exercise. A clearly stated Charter of Rights for all people, regardless of their background and health situation and health literacy is needed. Increasingly important is to provide people living with cognitive decline and dementia an accessible and supportive document to outline their rights. It should also include an acknowledgement of support for people and advocates who may be brought in to advocate for people living with frailty and vulnerability in older age.

Of particular concern is the lack of detail concerning the principles of consumer directed care, which underscore the provision of services in the Home Care Packages program[1].

The six key principles being;

- Consumer Choice and Control

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[1] Consumer directed care—choice and flexibility https://www.legislation.gov.au/Details/F2015L01016

- Rights
- Respectful and Balanced partnerships
- Participation
- Wellness and Reablement
- Transparency

The current Charter of Rights and Responsibilities covering Home Care states that each care recipient should be assisted to set goals in relation to the outcomes from home care, determine the ongoing involvement and control in the provision of home care, choose the care and services that best meet the goals and in particular have a representative participate in decision relating to care is needed due to a lack of capacity. Of particular importance is the explicit understanding in the current home care rights that;

(a) to receive reliable, coordinated, safe, quality care and services which are appropriate to meeting his or her goals and assessed needs;

(b) to be given before, or within 14 days after, he or she commences receiving home care, a written plan of the care and services that he or she expects to receive;

(c) to receive care and services that take account of his or her other care arrangements and preferences;

(d) to ongoing review of the care and services he or she receives (both periodic and in response to changes in his or her personal circumstances), and modification of the care and services as required.

And concerning rights around the budget and statement of available funds;

(a) to receive an individualised budget for the care and services to be provided;

(b) to have his or her individualised budget reviewed and, if necessary, revised if:

(i) the care and services to be provided, or the costs of providing the care and services, change; or

(ii) he or she requests the approved provider to review and, if necessary, revise the individualised budget;

(c) to receive a monthly statement of the funds available and the expenditure in respect of the care and services provided during the month.[2]

The absence of such detail in the current draft Charter of Rights raises concerns that the provider may bypass the need to understand and respond appropriately to consumers' needs

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[2] Schedule 2—Charter of care recipients' rights and responsibilities—home care, available at https://consultations.health.gov.au/aged-care-policy-and-regulation/the-australian-charter-of-aged-care-rights/supporting_documents/Charter%20of%20care%20recipients%20rights%20and%20responsibilities%20%20home%20care.pdf

in these areas. It should also be stated in the Charter of Rights that the care and services delivery should be provided with professional skill and competence.

3. Should the Charter be phrased in the first person, 'I have the right to' or 'you have the right to'?

An ‘I’ statement approach is preferred – I have the right to – however, for people who are not able to fully comprehend the concept or importance of the draft such as people living with dementia and cognitive decline the statement needs to be inclusive and respectful of support structures. It would be preferred to open each Right with ‘**I have the right to or be supported to…’**

In the absence of acknowledgement of support people in the current draft Rights there exists a situation that for people who are not empowered to understand or to exercise their rights that they will simply not be considered, due to a lack of comprehension of the importance of such Rights. It is imperative that ALL people be included in the spirit of the rights; particularly so as significant numbers of people accessing government aged care services and supports are living with dementia or cognitive decline.

4. Are the rights in the draft Charter easy to understand?

The feedback received from Dementia Australia from carers and advocates mostly stated that the language is written in a way that is understood, however, there were some references to the vagueness of language used in the draft Charter as described in the feedback below;

The language is easy to understand however is vague and could include explanatory notes such as ‘high quality’ what does ‘high quality’ care mean? What does it involve? Consumers have a right to receive comprehensive information about their care and what it looks like. This is particularly important for people living with dementia.

Carer of a person with dementia

In summary, terms such as ‘high quality’ need to be further explored and defined within the Charter of Rights or in the accompanying intent of the right or in any explanatory material.

5. Would you add any additional rights to the Charter?

Dementia Australia has consulted widely with its advocates and people living with dementia and they have expressed the following;

The charter does not include any reference to support people living with cognitive decline. There needs to be a strong emphasis included for provision of advocates and supporting the inclusion of advocates in the policies of aged care providers. This is particularly the case in g) I have the right to maintain control over, and continue to make decisions about, my care and personal and social life

Consumers are supported to maintain control and make decisions, including to: take risks to live the best life they can; choose who to have relationships with; enjoy social engagements outside the service;

and express their views in matters affecting them. Consumers can say no or change their mind at any time.

Suggest the inclusion of the right to supported decision making and involvement of carers or family members to help people living with dementia have informed choice. Empowering people living with dementia by aiding them to make decisions about their care and treatment as early as possible to enhance and better meet their needs and rights.

This is somewhat picked up in i) I have the right to choose to have another person speak on my behalf but could be further reinforced.

Carer of a person with dementia

6. Would you remove any rights from the draft Charter?

No Rights should be removed as it currently stands.

7. Would you change any rights in the draft Charter?

Dementia Australia would like to suggest the following changes;

Item (a) intent of this right, Dementia Australia suggests the following wording - All consumers have the right to receive safe and high-quality care and services. Providers need to understand and respond appropriately to consumers' needs; ensure consumers understand the care and services they are to receive; and ensure staff are well supported with education and resources to deliver these services.

Item (b) I have the right to be treated with dignity and respect and to have my individuality valued, replace 'individuality valued', to needs and preferences valued and respected.

Item (f) to include 'be assured if I have any form of dementia that my family or carer will be afforded the same rights on my behalf.

Item (h) to include 'be listened to and have reflected back to me that I have been understood'.

Item (i) alter the wording from 'choose to have another person speak on my behalf; to 'Have the person of choice speak on my behalf'.

Item (j) the current Right covering complaints makes an assumption that a person is empowered as such to make a complaint. Dementia Australia seeks to have this Right include the mechanism by which a person who requires support, such as someone living with dementia would be able to raise a complaint. The suggestion here is to alter the Right to include 'express concerns and be assisted to make a complaint and have a complaint dealt with fairly and promptly'.

8. How else could consumers be made aware of their rights under a single Charter?

Consumers should be communicated their rights when they receive confirmation of their aged care service from the Department of Health or the future Aged Care Quality and Safety Commission which will come into effect on January 1, 2019.

The Charter of Rights should also be;

- Available on the My Aged Care website
- Available on the My Health Record web link
- Distributed by Regional Assessment Service (RAS) and Aged Care Assessment Team (ACAT) assessors at the time of assessment
- Made available during consultations with prospective providers of aged care services
- Circulated by the Department of Health with any communication around assignment and approval of Home Care Packages
- Made available on websites of residential service providers and distributed when discussing and delivery of residential agreements
- Distributed by Case Managers to discuss when developing care plans with clients
- Made available when applying for attorney status through the Power of Attorney application process

9. Do you have any other comments?

The move to a single charter of Rights across all of the aged care service programs is a positive step towards achieving a universal consensus of understanding about the rights of older Australians receiving Commonwealth subsidised aged care. This can be achieved through the current consultation mechanism which is being undertaken by the Department. It is important that the needs of people living with dementia are reflected in the Rights as they represent a significant number of aged care consumers.

Dementia Australia has consulted with advocates and carers of people living with dementia on the draft Single Charter of Aged Care Rights. Our advocates have raised some concerns about the accessibility of the Rights and acknowledgement within the Rights of the needs of people living with dementia, particularly as people who are not always able to speak for themselves. Additionally, some of our advocates indicated that the draft Charter was a positive measure requiring additional specificity for people living with dementia. The following comments are indicative of the feedback received;

…my concerns lay in the fact that probably at least half of the residents in Aged Care Facilities have dementia, so for the most part, are unable to engage with this Charter. [This should] not mean… that they are not entitled to the same rights.

I would like the Charter to express that the family and carers of people with dementia be afforded these exact same rights. I know that is in the Introduction, but I feel strongly that it needs to be included more firmly in the actual Charter.

I am a person in this position and have carved a way into being included in every aspect of my husband's care. All decisions are made only after discussion with me and after my consent has been given…I am integral to my husband's care and consider myself one of the care team and am accepted as such, at all levels.

This type of involvement is something that should be accepted and therefore needs to be embraced more solidly within the Charter.

Carer of a person living with dementia

I think it is really good and obviously a lot of time and care has gone into the wording. It just needs to be a bit more specific about the fact that for people with dementia, who are not able to make decisions about their care or understand their rights, their family or an advocate must take on that responsibility to ensure their rights are upheld and the care facility must consult and keeps them fully in the loop regarding the person's care. It is far too easy to abuse and neglect a person with dementia and monitoring this can be very difficult even with the Charter of Consumer Rights.

Thank you for giving me the opportunity to read and comment on this very important document.

Carer of a person living with dementia

Dementia Australia is available to discuss any of the points raised in this submission and looks forward to working with the government to developing a Charter of Rights which fully supports the needs and preferences of people living with dementia.

Thank you for the opportunity to provide feedback into this very important document.

Yours Sincerely,

Maree McCabe
CEO
Dementia Australia