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# AMA submission to the Department of Health – the draft Charter of Aged Care Rights

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## Background

The AMA thanks the Department of Health for the opportunity to provide feedback on the draft Charter of Aged Care Rights (the Charter). The AMA supports the principles of the Charter, however on its own will do little to protect the rights of aged care consumers. The Charter must be accompanied with adequate guidance and compliance measures.

## Guidance and amendments to the Charter

The AMA understands that fact sheets aimed at consumers will accompany the Charter. Like the Australian Charter of Healthcare Rights<sup>1</sup>, the Charter should include supporting guidance for each of the stakeholder groups. This includes consumers (and their families, carers and substitute decision-makers) and aged care providers (and their staff). The Charter and guidance documents must be easily understandable and accessible to all stakeholders, including Culturally and Linguistically Diverse (CALD) individuals, and those with a visual, hearing, or other disability. The Charter and guidance documents should also be displayed in aged care settings and provided as an information package to older people and their carers when they enter the aged care system.

The draft guidance documents should also be consulted on publicly before they are implemented.

The AMA suggests including a table in a guidance document which outlines the transition between the old and new Charters. This will assist stakeholders in clearly understanding what has changed. The table should include aspects that have been deleted because they have been included in the new Aged Care Quality Standards (the Standards) or already exist in other legislation, or the Government considers they are protected/covered under broader provisions in the new Charter.

It is also unclear how aged care providers will be obligated to comply with the Charter in the context of the Aged Care Quality Standards, the *Aged Care Act 1997* and other relevant legislation. This information should also be included in the guidance documents.

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<sup>1</sup> <https://www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/>

a) Receive safe and high-quality care and services

Older people receive care and services from a wide range of providers. This includes health professionals who are independent from the aged care provider organisation. Australia's health and aged care systems are complex, and it is sometimes difficult for consumers to understand under which system they are receiving their services from. While older people have the same right as other ages to "have the highest possible standard of physical and mental health"<sup>2</sup>, some aged care providers do not meet their responsibilities concerning clinical care. The '2.4 clinical care' Accreditation Standard was the second highest outcome not met by RACFs in 2016-17, followed by '2.7 – medication management'<sup>3</sup>. Medication administration and management was the most common complaint made about RACFs in 2017-18<sup>4</sup>. Therefore, it is important that consumers understand that their right to "receive safe and high-quality care and services" includes health care services. This includes ensuring that aged care providers are aware of their responsibilities to facilitate timely access to health professionals, such as the consumer's nominated GP. The guidance document should highlight that safe and quality care and services includes health care.

c) Have my identity, culture, and diversity valued and supported

The guidance documents should clarify that religious rights are also included under this Right. Australians have diverse religious beliefs and non-religious values, and these should also be valued and supported. Consumers should have the choice to be supported to practice their religious beliefs or non-religious values.

d) Maintain my independence

The AMA believes that this Right should be amended to state "maintain my independence to the greatest extent possible". Sometimes, maintaining an older person's independence may not be in the consumer's, or the public's, best interests or safety.

For example, a resident with vascular dementia but otherwise in good physical condition is a good example of fluctuating decision-making ability where the resident may not understand why they need to be in care and might subsequently try to 'abscond' back to their former home. The Charter implies the resident has a right to do so but of course that would not be in their best interests. If this resident exhibits sundowning behaviour (i.e. confusion, anxiety, aggression, etc.), roaming freely would threaten significant risk to the resident and the public. Adding "to the greatest extent possible" means that the consumer can still maintain their dignity, be respected, and maintain their independence in a safe manner.

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<sup>2</sup> <https://www.safetyandquality.gov.au/wp-content/uploads/2012/01/Charter-PDF.pdf>

<sup>3</sup> Australian Aged Care Quality Agency (2017) *Annual Report 2016-2017*, p13

<sup>4</sup> Aged Care Complaints Commissioner (2018) *Annual Report 2017-18*, p20

e) live without abuse and neglect

The World Health Organisation defines elder abuse as:

“a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person. Elder abuse can take various forms such as financial, physical, psychological and sexual. It can also be the result of intentional or unintentional neglect.”<sup>5</sup>

There are several challenges around defining elder abuse<sup>6</sup> and this can confuse consumers when understanding and acting on their rights. A clear definition of elder abuse is required in the guidance document.

The guidance documents should also include information concerning the prevention, recognition, intervention and management of elder abuse. While the prevalence of elder abuse in Australia is unknown, there are indications that it is around 20<sup>7</sup>-27<sup>8</sup> per cent and this will likely increase with an ageing population<sup>9</sup>. It is important that consumers and aged care providers are aware of methods to prevent elder abuse.

g) maintain control over, and continue to make decisions about, my care and personal and social life

The AMA is a strong supporter of a consumer’s right to make their own care decisions<sup>10</sup>. However, their decision must be an informed decision. It is important that consumers understand the level of risk that comes with aspects of their care. For example, using alternative medicine to treat a health condition that has no evidence-base for its effectiveness in treating that condition.

Therefore, the provider responsible for implementing the care must communicate effectively with the consumer (or a substitute decision maker, where relevant) the risks that come with refusing or accepting a care method or choosing an alternative care method. The provider must then obtain the consumer’s consent before proceeding.

The AMA’s [Health and care of older people](#) position statement outlines the following on consent and decision making:

“Older people have the same rights as others to make their own informed health care decisions including the right to accept, or reject, advice regarding treatments and procedures.

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<sup>5</sup> [http://www.who.int/ageing/projects/elder\\_abuse/en/](http://www.who.int/ageing/projects/elder_abuse/en/)

<sup>6</sup> Australian Law Reform Commission (2017) *Elder Abuse – A National Legal Response*, p37-40

<sup>7</sup> Australian Law Reform Commission (2017) *Elder Abuse – A National Legal Response* p37

<sup>8</sup> Australian Medical Association (2018) *2017 AMA Aged Care Survey Report*, p20

<sup>9</sup> Australian Institute of Health and Welfare (2017) *Australia’s Welfare 2017*, p179

<sup>10</sup> <https://ama.com.au/system/tdf/documents/AMA%20Code%20of%20Ethics%202004.%20Editorially%20Revised%202006.%20Revised%202016.pdf?file=1&type=node&id=46014>

Where an older person has limited, impaired or fluctuating decision-making capacity, they should be supported to participate in decision-making consistent with their level of capacity at the time a decision needs to be made (any assessment for capacity for health care decision-making is relevant to a specific decision at a specific point in time). This includes decisions involving their health care as well as the use and disclosure of their personal information.

Some patients will have capacity to make a supported decision while others will require a substitute decision-maker.”

In terms of medical care, a substitute decision-maker (SDM) is a person appointed or authorised by law to make substitute decisions on behalf of a person who no longer has the capacity to make their own informed decisions<sup>11</sup>. It will be important to engage with the relevant State and Territory guardianship authorities to ensure consumers understand their rights in appointing an SDM.

Advance care planning is another essential component of upholding consumers’ rights to make their own health care decisions. In terms of medical care, advance care planning is a process of planning for future health and personal care whereby a person’s values, beliefs and preferences are made known, so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions. The AMA strongly suggests engaging with organisations such as Advance Care Planning Australia who provide relevant guidance to consumers and professionals on advance care planning more broadly as well as legal requirements across the States and Territories.

The above information also applies to the right to “choose to have another person speak on my behalf”.

### *Decision making support*

As in the current Charter of Rights for home care<sup>12</sup> and Standard 1 of the Aged Care Quality Standards<sup>13</sup>, consumers must also be supported when choosing their care. This should include support from the government. A consumer has up to 84 days to enter into a home care agreement and if they surpass this timeframe, their home care package will expire, and they will need to reapply<sup>14</sup>. The AMA has heard from stakeholders in the sector that it is usually taking a long time for consumers to choose a home care agreement, and some do not choose one at all. Letters are sent to the consumer at around 35 days to remind them to enter into a home care agreement. Letters can be easily lost and there should be multiple avenues to follow up with a consumer, such as a phone call. Further, AMA members have consulted with individual aged care providers to understand the waiting times consumers were experiencing, and providers reported

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<sup>11</sup> AMA Position Statement on End of Life Care and Advance Care Planning 2014

<sup>12</sup> User Rights Principles 2014, Schedule 2

<sup>13</sup> [https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/07\\_2018/aged\\_care\\_legislation\\_amendment\\_single\\_quality\\_framework\\_principles\\_2018.pdf](https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/07_2018/aged_care_legislation_amendment_single_quality_framework_principles_2018.pdf)

<sup>14</sup> <https://www.youtube.com/watch?v=PQtsUgeLVWI&feature=youtu.be>

that they were not receiving any referrals. This was also reflected in several media reports<sup>15</sup>, and Leading Aged Services Australia (LASA)'s My Aged Care home care provider survey – where 50 per cent of providers reported a decline in the number of packages received, and there were also common comments on low numbers in activated home care packages, and increased consumer confusion with the new correspondence processes<sup>16</sup>.

The AMA understands that the government intends to trial information and community hubs and additional staff to support consumers in navigating and making decisions about aged care<sup>17</sup>. Consumers need to be aware of these services once implemented and be able to exercise their right to support from both the government and aged care providers.

#### j) complain, and to have my complaints dealt with fairly and promptly

There should be adequate information in the guidance document regarding how to lodge a complaint to both the aged care provider, and the Aged Care Quality and Safety Commission (who will be replacing the Aged Care Complaints Commissioner 1 January 2019). This should also include supporting access to aged care advocates.

The guidance documents should also include that consumers have the right to complain in confidence and should emphasise that the right to “exercise my rights without it adversely affecting the way I am treated” includes when making a complaint. Many consumers withhold complaining because they are fearful of the repercussions.

The AMA acknowledges that the Standards<sup>18</sup> obligate providers to support consumers when making a complaint. This should also be included in the guidance documents, so consumers are aware of this.

### **Conclusion**

The Charter sets out good, clear principles towards communicating older consumer's (and their family's and carer's) rights when accessing Commonwealth-subsidised aged care services. The AMA suggests more detail should be provided through guidance documents. This would ensure consumers are fully aware of their rights under the new Charter. Guidance documents should target consumer groups and aged care providers separately. These documents must be easy to understand and accessible to everyone, including those who require extra assistance due to a disability, language or cultural barrier. The draft guidance documents should be open to public consultation before being implemented to ensure they are adequate.

The AMA suggests one amendment to the wording of the Charter – to add “to the greatest extent possible” to the end of Right (d) to ensure the Charter reflects the reality of working with older consumers whose behaviours may on occasion not be in the best interest of themselves or the public.

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<sup>15</sup> <http://www.australianageingagenda.com.au/2017/05/19/confusion-reigns-new-aged-care-queue/>

<sup>16</sup> <https://lasa.asn.au/wp-content/uploads/2017/06/Home-Care-Reforms-Info-Series-13-FINAL.pdf>

<sup>17</sup> <http://health.gov.au/internet/budget/publishing.nsf/Content/budget2018-factsheet77.htm>

<sup>18</sup> Standard 6 – feedback and complaints, p9-10

The AMA does congratulate the Department on the complex task of simplifying multiple documents into something that is clear, concise, and informative as a draft for consultation.

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