

31 January 2023

National Dementia Action Plan  
MDP 765, GPO Box 9848  
CANBERRA ACT 2601

Via email: [dementioplan@health.gov.au](mailto:dementioplan@health.gov.au)

### **National Dementia Action Plan Consultation Feedback**

Thank you for the opportunity to comment on this consultation draft in relation to the development of the National Dementia Action Plan (the Action Plan).

As the Public Advocate for Queensland, I undertake systemic advocacy to promote and protect the rights and interests of Queensland adults with impaired decision-making ability.<sup>1</sup>

People with impaired decision-making ability are a broad and diverse group due to the range of conditions that may affect a person's decision-making ability, which includes dementia. Not all people with dementia have impaired decision-making ability, however many may experience this due to the progressive nature of this condition.

In relation to the proposed Action Plan, I would like to put forward the following for consideration.

#### **Recognition and promotion of the rights of people with dementia**

The previous dementia action plan, the *National Framework for Action on Dementia 2015-2019*, included the principle that 'people with dementia are valued and respected, including their rights to choice, dignity, safety (physical, emotional and psychological) and quality of life.'<sup>2</sup>

However, it is noted that a similar principle recognising the human rights of people with dementia has not been included in the current Action Plan.

Some relevant concepts have been included in the outcome statement relating to *Objective 1: Tackling stigma and discrimination*, which includes that 'people with dementia and their carers can fully participate, feel safe and empowered to live independently with respect and dignity, free from stigma and discrimination'.

However, it is important that the Action Plan as a whole has as its base the protection and promotion of human rights, as these concepts should inform each of the Objectives. It is also important that the Action Plan is inclusive of all of the rights held by people with dementia.

It is recommended that the Action Plan should make reference to the fundamental human rights principles described in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which applies to people with dementia.<sup>3</sup>

---

<sup>1</sup> *Guardianship and Administration Act 2000* (Qld) s 209.

<sup>2</sup> Department of Health and Ageing, *National Framework for Action on Dementia 2015-2019*, p. 2.

<sup>3</sup> United Nations. *Convention on the rights of persons with disabilities*, GA Res 61/106, 76<sup>th</sup> plen mtg, UN Doc A/RES/61/106 (adopted on 13 December 2006).

Several of the following points below highlight opportunities to further consider and promote the rights of people with dementia throughout this Action Plan.

## Decision-making

The UNCRPD states that all people with disability have a right to participate in the making of decisions that affect them.<sup>4</sup>

During a discussion with people with lived experience of dementia held as part of the Adult Safeguarding Project undertaken by my office, we heard that people with dementia feel as though they are often not afforded the opportunity to be involved in decision-making. They also noted that it is often assumed by the community, as well as by professionals that they may interact with across different systems, that they lack capacity for decision-making once they have been diagnosed with dementia even though, for many people, this is not the case.

As noted under Objective 1 of the Action Plan, it is important that education and awareness raising is conducted to educate the community about dementia. This should include information to help address the often-limiting assumptions people may have about decision-making ability, and promote opportunities for people with dementia to participate in decision-making.

Within the proposed plan, under *Objective 4: Improving treatment, coordination and support along the dementia journey*, supported decision-making has been noted as important for enabling people with dementia to take part in decision-making and as a safeguard against abuse and exploitation.

For people with dementia who may require assistance with decision-making, or who have a decision-maker appointed, it is critical that they are supported to participate in decision-making to the greatest extent possible. Where this participation is not possible, it is critical that any decisions made by an appointed decision-maker reflect the wishes and preferences of the person with dementia.

The related suggested action in the Action Plan, 'improving access to information about supported decision-making in each jurisdiction'<sup>5</sup>, could help to promote the use of supported decision-making. It should be noted, however, that this action is included in the full consultation document as opposed to the summary document which does create some confusion.

Other concepts and issues that may also assist in promoting the autonomy and decision-making of people with dementia, which could be considered in the context of the Action Plan include:

- **Dignity of risk:** Dignity of risk refers to affording people the right to make choices that others may consider risky or that they may not agree with. Supporting people to make these types of decisions may be challenging at times for family members and others who care for and support the person with dementia, who may hold concerns about how the decision will affect the person's safety and wellbeing. However, impeding dignity of risk can negatively impact personal growth, self-esteem, and overall quality of life.<sup>6</sup>
- **Documenting wishes and preferences:** It is also important to increase awareness and understanding of legal documents that can assist people in planning for the future and in documenting their wishes and preferences, including enduring powers of attorney (or their equivalent in other states and territories) and advance health directives.

People need to be able to access information about these documents as early as possible, as they must be completed while a person has decision-making capacity. It is also important that the person completing the relevant instrument, as well as the person (or people) being

---

<sup>4</sup> United Nations. *Convention on the rights of persons with disabilities*, GA Res 61/106, 76<sup>th</sup> plen mtg, UN Doc A/RES/61/106 (adopted on 13 December 2006).

<sup>5</sup> Department of Health and Aged Care, *National Dementia Action Plan: Public Consultation Paper*, p. 46.

<sup>6</sup> J. Ibrahim and A. Davis, 'Impediments to applying the "dignity of risk" principle in residential aged care services', *Australasian Journal on Ageing*, vol. 32, no. 3, 2013, pp. 188-93.

nominated as potential future decision-maker(s), understand the relevant obligations, including the need to involve the individual to the greatest extent possible in any decisions being made on their behalf.

Promoting uptake and a better understanding of these documents could also help to prevent misuse of enduring powers of attorney.

- **Access to advocacy:** Access to independent advocacy can also help to protect the rights and wellbeing of people with dementia. Advocates can support people to understand their situation and options, voice their preferences, concerns and complaints, and navigate complex systems.

Despite the benefits of advocacy, many people may not be aware of the types of advocacy services available or how to access them. The current high demand for advocacy can also limit opportunities for engagement with advocates.

Improved access to advocacy for people with dementia could facilitate participation in decision-making and help to ensure they receive appropriate care and support that reflects their needs and preferences. The importance of advocacy was also recognised by the Royal Commission into Aged Care Quality and Safety, with its final report making recommendations to increase access to advocacy for older adults.<sup>7</sup>

### Restrictive practices

The proposed Action Plan makes reference to including a reduction in the use of restrictive practices for people living with dementia as a potential measure of performance related to *Objective 4: Improving treatment, coordination and support along the dementia journey* and *Objective 6: Building dementia capability in the workforce*. However, the actions within the plan that this outcome would be linked to are not clear.

The use of restrictive practices significantly affects the human rights of the person involved, so the use of these practices must follow appropriate authorisation processes, with the aim of minimising, or ideally eliminating, the use of restrictive practices.

I have previously written about my concerns regarding the *Quality of Care Principles*, including a restrictive practices reform options paper that I released on 5 October 2021,<sup>8</sup> as well as three opinion pieces published in *Australian Ageing Agenda* in 2022.<sup>9</sup>

A key concern is how national legislation relating to the authorisation of restrictive practices interacts with varying state and territory legislation, to create a system that is complex, difficult to understand, and presents a number of operational challenges.

I have previously made two key recommendations relating to restrictive practices.

First, in order to avoid this confusion, it should be recognised that restrictive practices are best regulated by State and Territory governments, rather than by the Australian Government. This could be addressed by amending the *Quality of Care Principles* to require that 'authorisation for the use of the restrictive practice is to be given in compliance with any applicable law of the state or territory in which the care recipient is provided with aged care'.

Second, the current consent/ substitute consent model used to regulate aged care restrictive practices is not optimal. This is because requiring a person who will be subject to restrictive practices to provide consent to do so is not particularly meaningful, and substitute decision-makers often do

---

<sup>7</sup> Commonwealth Royal Commission into Aged Care Quality and Safety, *Final report: Care, dignity and respect, Volume 1 summary and recommendations* (2021).

<sup>8</sup> The Public Advocate (Qld), *Improving the regulation of restrictive practices in Queensland: A way forward*, reform options paper, 5 October 2021.

<sup>9</sup> J. Chesterman, 'Stopping the inappropriate use of restrictive practices', *Australian Ageing Agenda*, 2022; J. Chesterman, 'Proposed restrictive practice changes "deeply flawed"', *Australian Ageing Agenda*, 2022.; J. Chesterman, 'Are we regulating or regularising aged care restrictive practices', *Australian Ageing Agenda*, 2022.

not have the clinical expertise necessary to determine if there are other less restrictive ways to manage the situation that has led to the potential use of restrictive practices.

Instead, I have advocated for the adoption of a senior practitioner model, which would include the appointment of a Senior Practitioner who would provide authorisation for, and oversee the use of, restrictive practices.

Reform to current authorisation processes is required to address the complexity of the current system and to help to reduce and ideally eliminate the use of restrictive practices.

### **References to other key strategies and plans**

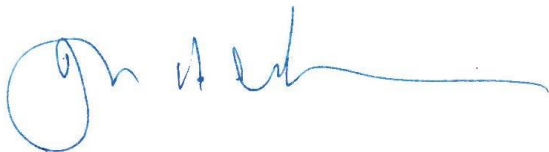
Dementia should not be viewed in isolation as one health condition requiring only a health response. People with dementia may also experience a range of other health conditions and situations following their diagnosis, requiring interaction with a range of services and systems.

While the full consultation document for the Action Plan makes reference to several existing plans and strategies, including the National Preventative Health Strategy, the National Palliative Care Strategy, and the Younger People in Residential Aged Care Strategy, the Action Plan should also be linked to other relevant National and State and Territory strategies and plans such as:

- Australia's Disability Strategy 2021-2031 and related Targeted Action Plans
- The National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023
- The National Agreement on Closing the Gap
- Relevant state and territory strategies for older adults, people with disability, and carers.

Thank you for the opportunity to provide feedback regarding the proposed National Dementia Action Plan. If you require clarification of any of the issues raised in this correspondence, please contact my office on 07 3738 9513.

Yours sincerely



John Chesterman (Dr)  
**Public Advocate**