



# **A Wellness and Enablement Approach for People Living with Dementia**

A submission to the Royal Commission into Aged Care Quality and Safety

28 July 2020

## **About Dementia Australia**

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia yet remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

## Introduction

Dementia Australia was pleased to see Counsel Assisting's reference in the draft proposals on Program Design to wellness, reablement and rehabilitation services being provided irrespective of cognitive status. This specificity addresses a key challenge people living with dementia experience in accessing such services in the current aged care system, namely that they are typically not considered eligible for reablement due to the progressive nature of dementia.

In our response to Counsel's Assisting Submissions, Dementia Australia recommended building a more thorough evidence base for what an optimal package of wellness and enablement services would look like and how it might make the most difference to the independence, autonomy and quality of life for people with dementia. This submission is, in part, designed to begin building that evidence base, and to inform the final recommendations for the Royal Commission into Aged Care Quality and Safety.

There is a widespread assumption in the aged care system that, because people with dementia are experiencing a progressive decline rather than having a disease trajectory with an obvious restorative path, they are not suitable candidates for wellness and reablement approaches. For this reason, we will instead reframe our proposal in the language of *enablement* services – supports that can *enable* a person living with dementia to maintain their functional capacity and independence for as long as possible.

## Wellness and enablement for people living with dementia

*“In the absence of a cure or ability to significantly modify the course of the disease, the message for policy makers, practitioners, families, and persons with dementia needs to be “living well with dementia”, with a focus on maintaining function for as long as possible, regaining lost function when there is the potential to do so, and adapting to lost function that cannot be regained. Service delivery and care of persons with dementia must be reoriented such that evidence-based reablement approaches are integrated into routine care across all sectors.”<sup>1</sup>*

The Commonwealth Home Support Programme (CHSP) guidelines define wellness as emphasising identifying needs, aspirations and goals. It acknowledges and builds on strengths and has a focus on integrating support services as a path to greater independence and quality of life. Reablement emphasises assisting people to regain functional capacity and improve independence. Similar to rehabilitation, it is time limited, goal-oriented and aims at full recovery where possible – it seeks to enable people to live their lives to the fullest.<sup>2</sup>

Dementia Australia argues that a concept of enablement is more appropriate, especially for people living with dementia. This approach would focus on supporting people with dementia throughout the disease progression to maintain function and independence for as long as possible.

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<sup>1</sup>Poulos, J. et al (2017) A comprehensive approach to reablement in dementia, *Alzheimer's Dementia* (NY) 3(3): 450–458

<sup>2</sup>Department of Social Services (2015) *Living Well at Home: Commonwealth Home Support Programme Good Practice Guide*

A package of services and supports designed to enable people living with dementia could include:

- Occupational therapy – assessment of function, strategies to undertake activities of daily living, identification of environmental changes and home modifications.
- Speech pathology – support for dysphasia and other communication challenges
- Counselling – support to understand and process the diagnosis of dementia.
- Exercise physiology and physiotherapy – functional exercises, strength and balance exercises for falls prevention.
- Dietetics – nutrition advice and meal support.
- Cognitive rehabilitation – although there is no conclusive evidence to support the use of cognitive interventions with people with dementia, there is no evidence of harm, and this approach *could* support the maintenance of cognitive function.
- Psycho-social interventions and peer supports – opportunities for positive engagement with other people living with dementia.
- Tailored supports to participate in meaningful activities – for example, a skilled dementia support worker/volunteer who supports a person with dementia to continue to participate in sport/leisure activities.

An enablement approach to support and care for people living with dementia can ensure that individuals are encouraged and supported to act as independently as possible, for as long as possible, allowing them to make most of their abilities, stay active and participate in meaningful activities. Adopting an enablement approach also reduces the sense of ‘feeling helpless’ as people with dementia experience a progressive loss in their abilities. By supporting the independence and participation of people living with dementia, enablement services could slow the demand for more intensive services (and this shift in approach will ensure that the effectiveness of such interventions can be more comprehensively assessed from the point of view of outcomes and economic efficiencies).

For example, a pilot study of the Interdisciplinary Home-based Reablement Program (I-HARP) conducted between 2015 and 2016 with 18 people with dementia and their carers showed potential benefits in terms of individual goal attainment, mobility, independence, well-being and confidence. Participants commented that focusing on their abilities was reassuring and gave them a feeling of hope and independence. Reasons for success of the program were attributed to the one-on-one, hands-on approach; continuity and regularity of visits; and specialised yet easy-to-follow suggestions from each clinician. Within 12 months of taking part in the study participants had fewer falls, fewer hospital admissions and none had moved into residential aged care.<sup>3</sup>

However, it should be acknowledged that the evidence-base for reablement/enablement interventions for people with dementia is still in development and more research is needed.<sup>4</sup>

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<sup>3</sup>Yun-Hee Jeon, Luisa Krein, Judy M. Simpson, Sarah L. Szanton, Lindy Clemson, Sharon L. Naismith, Lee-Fay Low, Loren Mowszowski, Peter Gonski, Richard Norman, Laura N. Gitlin & Henry Brodaty (2019) Feasibility and potential effects of interdisciplinary home-based reablement program (I-HARP) for people with cognitive and functional decline: a pilot trial, *Aging & Mental Health*, DOI: 10.1080/13607863.2019.1642298  
More information available at <https://www.sydney.edu.au/medicine-health/our-research/research-centres/i-harp.html>

<sup>4</sup>An overview of the existing evidence for reablement approaches for people living with dementia is provided in O’Connor CM, Poulos CJ, Gresham M, Poulos RG.(2019) Supporting independence and function in people living with dementia, A technical guide to the evidence supporting reablement interventions (2nd Edition). Sydney:

While we recognise that we do not yet have a systematic evidence base to prove that a wellness and enablement approach slows cognitive decline, minimises the need to use other services (e.g. acute care), or delays premature entry into residential aged care, we see enough anecdotal evidence that enablement services (when they are available) make a difference to the lives of people living with dementia, as well as their families and carers.

Recently developed resources for providers and consumers (funded by the Cognitive Decline Partnership Centre and published by HammondCare) provide guidance and advice as to how a reablement approach should be implemented in home care for people living with dementia.<sup>5</sup> Yet we continue to hear reports that people with dementia are denied access to reablement and are deemed ineligible because of the progressive nature of their condition.

Dementia Australia therefore proposes that the following process be implemented by the health and aged care systems (and supported by Government) to ensure that a wellness and enablement approach for people with dementia is integrated into the aged care system.

1. Provide improved diagnostic and service planning pathways that identify key allied health, mental health, psychosocial and/or primary health supports that will help a person in the earlier stages of dementia to maintain independence and autonomy for as long as possible.
2. Implement regular reviews to ensure service appropriateness is maintained.
3. Develop an evidence base on the impact of enablement services for people with dementia, families and carers.
4. Conduct an analysis on the viability of funding models that includes:
  - a. enablement as universal health care offering (including alignment with the Medicare Benefits Schedule (MBS) and GP item numbers);
  - b. as a discrete service stream for people with dementia, offered through the National Dementia Support Program (NDSP) or similar;
  - c. inclusion in CHSP and/or home care packages.

## **A post-diagnostic wellness and enablement program of support**

Dementia Australia also advocates for the development of an early intervention approach to wellness and enablement. Although we support the principles underpinning CHSP and home care packages, unfortunately, for many people with dementia, by the time they access these services, especially a home care package (commonly at a level well below what is needed), it is too late to implement wellness and enablement approaches – dementia has progressed and the opportunity to maintain their independence and function has passed. Dementia Australia therefore recommends that wellness and enablement approaches should be made available as a post-diagnostic support for people living with dementia.

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HammondCare. Available at <https://www.hammond.com.au/documents/reablement-guides/480-hc-technical-guide-2019-2nd-edition/file>

<sup>5</sup>Poulos CJ, Gresham M, Poulos RG, Maurice C, O'Connor, CM.(2019) *Supporting independence and function in people living with dementia, A handbook of reablement programs for service providers and others with an interest in improving function* (2nd Edition). Sydney: HammondCare and

The Clinical Practice Guidelines for Dementia in Australia<sup>6</sup> recommend wellness and reablement type services and activities (for example, as occupational therapy, exercise) as post-diagnostic supports however these are not routinely prescribed to people with dementia. All too often, people with dementia, their families and carers report that a diagnosis of dementia is delivered alongside a suggestion to “get your affairs in order” and an attitude of “there is nothing I can do for you”. Kate Swaffer, CEO of Dementia Alliance International, describes this process as “prescribed disengagement” which then sets up a chain reaction of defeat and fear, and negatively impacts a person's ability to be positive, resilient and proactive.<sup>7</sup>

The Dementia Enablement Guides<sup>8</sup> developed by the Queensland Statewide Dementia Clinical Network in 2016 note that:

*“Assistance to maintain general, physical and mental health as well as chosen lifestyle and social / community involvement should be considered and a holistic care plan generated. Care plans which detail abilities, disabilities and goals should be reviewed regularly and referral to appropriate therapeutic interventions offered...Holistic assistance which encourages a person to live to his or her personal potential is the cornerstone of good care. By adopting an enabling approach focused on preferred occupation and meaningful activity, independence and wellbeing, people diagnosed with dementia and their care partners have an opportunity to live to their post-diagnosis potential.”*

These principles align with the view expressed by people with a lived experience of dementia. As Dementia Advocate, John Quinn states:

*“It is imperative that medical practitioners, particularly GPs, who make decisions about post-diagnostic care plans embrace the benefits of reablement; recommend evidence-based lifestyle preferences; and refer to appropriate allied health professionals.”<sup>9</sup>*

Dementia Australia recommends that a post-diagnostic wellness and enablement program of support for people living with dementia includes, at a minimum:

- Universal access to people with a diagnosis of dementia;
- Inclusion of people with dementia in goal setting to determine care/service planning;
- Assessment of current cognitive and physical functional abilities and identification of strengths to be maintained to support independence;
- Identification of programs and services that can support an individual’s wellness and lifestyle goals;

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<sup>6</sup>Guideline Adaptation Committee (2016) *Clinical practice guidelines and principles of care for people with dementia in Australia*, Sydney: NHMRC Partnership Centre for Cognitive and Related Functional Decline

<sup>7</sup>Swaffer, K. (2015) Dementia and prescribed disengagement, *Dementia: the international journal of social research and practice*, 14 (1):3-6

<sup>8</sup>Available at [https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0017/621710/dementia-enablement-guide.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0017/621710/dementia-enablement-guide.pdf) and [https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0031/621787/dementia-enablement-guide-consumer.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0031/621787/dementia-enablement-guide-consumer.pdf)

<sup>9</sup>Quinn, J. (2020) Putting Reablement into Practice, *Australia Journal of Dementia Care*, March Available at <https://journalofdementiacare.com/putting-reablement-into-practice/>

- Direct referral to required programs and services (e.g. occupational therapy, speech pathology, exercise physiology, dietetics, counselling, peer support, assistive technology, home modifications etc.);
- Flexibility to respond to changing needs as dementia progresses; and
- Regular reviews of goals and plans to ensure services/supports are appropriate.

“I would like [the government] to consider a case manager that works with the family. So you have one holistic management process. I could then go to the person who knows me, and when I get depressed I would know what to do. I need someone to develop a relationship who knows me, the family and circumstances.” Person living with dementia

A post-diagnostic wellness and enablement program of support needs to be individualised and flexible; it must not be prescriptive, but rather responsive to the changing goals and needs of people living with dementia, their families and carers. In this regard, the aged care sector can learn from approaches employed in the disability sector.

It is important that a program staff know the person and, in collaboration with the person with a diagnosis, make plans for support to enable them to maintain function and independence, and to respond to progressive, changing needs. A post-diagnostic wellness and enablement approach would be empowering for people living with dementia and integral to a pathway of continued wellbeing and support.

## Conclusion

Dementia Australia would welcome the opportunity to discuss this submission with Counsel Assisting and the Commissioners. We reiterate that a wellness and *enablement* approach in a redesigned aged care system needs to be implemented from, at a minimum, the point of diagnosis or at the point at which they access to an aged care service to ensure that people living with dementia are provided with opportunities to maintain their function and independence as much as possible, for as long as possible, rather than replicating the barriers and challenges they currently face in the existing system.