

Department of Health and Aged Care

***National Dementia Action Plan – Public
Consultation***

Occupational Therapy Australia submission

January 2023

Executive Summary

Occupational Therapy Australia (OTA) welcomes the opportunity to lodge a submission to the Department of Health and Aged Care (the Department) in response to the public consultation for the National Dementia Action Plan (NDAP).

The current dementia care system is fragmented, with no clear pathways between diagnosis and treatment and no collaboration between services. There is also a lack of rehabilitation services for people with dementia, and support for carers of people with dementia.

Given these shortcomings in the current services for dementia, OTA welcomes the NDAP and its objectives to create a system for dementia care that has more services and has a clearer pathway from diagnosis to treatment. OTA would also welcome the chance to assist the Department in implementing these reforms.

OTA is the professional association and peak representative body for occupational therapists in Australia. There are over 27,700 registered occupational therapists working in Australia. Occupational therapists are allied health professionals whose role is to enable their clients to engage in meaningful and productive activities. Occupational therapists assess and observe factors relating to a person, occupation (activity) and the environment.

Occupational therapists work with people living with dementia, and their carers, to identify their goals and help them find ways to achieve them through different strategies or by modifying their environment.

The following recommendations provide potential solutions to the above challenges and would allow occupational therapists to assist in reforming dementia care in Australia.

Summary of recommendations

Recommendation 1: Integrate the brain hubs outlined in the NDAP with dementia clinics to streamline the process between diagnosis and treatment

Recommendation 2: Modify the Chronic Disease Management Plan rebate to one which supports greater access to services for people living with dementia, and, encourage health professionals to work under this scheme.

Recommendation 3: Work with OTA to develop more effective rehabilitation services for people with dementia

Recommendation 4: Consider implementation of aspects of Scotland's Advanced Dementia Practice Model into the NDAP

Recommendation 5: Increase the use of the programs such as COPE and GREAT, to support people living with dementia.

Introduction

The role of occupational therapy in dementia care

Evidence based studies on the effectiveness of occupational therapy in dementia show that it can lead to improvements in the independence and quality of life of the person with dementia and improve quality of life for their carers (Laver et al., 2017; Bennet et al., 2019; Graff et al., 2007; Korczak, 2013).

Occupational therapists understand neurodegenerative diseases and other co-morbidities that may exist alongside dementia. They also have the skills to consider the personal, environmental, occupational, societal and institutional factors that may be enablers or barriers to a person with dementia.

When working with people living with dementia, occupational therapists assess the person's functional cognition and how dementia impacts their ability to perform everyday activities, and then work with the person to focus on how their strengths can enable them to participate in meaningful activities. Occupational therapists can enable people to overcome their challenges and enable them to engage in the things they want and need to do, supporting their wellbeing and quality of life.

Standard occupational therapy interventions for people with dementia include:

- Assessment of the home environment (either in person or remotely using telehealth) to ensure that the person-environment fit is appropriate. Home modifications and assistive devices are recommended when required.
- Problem solving in collaboration with the carer and person with dementia to achieve goals and overcome care challenges
- Carer education and skills training focused on how to optimise independence, prevent and manage symptoms, stay engaged in meaningful activities in order to improve quality of life, and link with other services.

(Laver et al., 2017)

There is also evidence to suggest that occupational therapy is a cost effective strategy in that it can cut down on medication and delay or prevent institutionalisation (Clarkson et al, 2017; Graff et al., 2008; Nagayama et al. 2015).

The current state of dementia care in Australia: A fragmented, disempowering system

When people are diagnosed with dementia they are too often given no information, no plan or hope. Instead, they are told to "go home and get your affairs in order." This is disempowering, considering that people with dementia will often have years where they can live well. Alzheimer's WA describes living well as not overlooking the real impacts of dementia, but that there are still ways to promote quality of life and have positive experiences (2022).

The pathway between diagnosis and treatment is further complicated by the lack of integration between services. People are currently diagnosed at state funded memory clinics or a private specialist, and then they may access services through home care packages, the

Commonwealth Home Support Programme, or the NDIS which are all federally funded. There is no communication or collaboration between the point of diagnosis and care provided.

Moreover, the dementia services that are generally available are not focused on rehabilitation and enabling people with dementia. People with dementia have reported that they want programs that focus on what they can do, not what they can't. It is currently difficult for them to access programs that address individual goals and promote independence and participation, and the rehabilitation services that are aimed at people with dementia are not widely known. There is also a shortage in services directed at supporting carers to manage care challenges.

Response to the NDAP

Initial comments

OTA welcomes the NDAP and its acknowledgement of the lack of integration between services and the lack of reablement options.

OTA supports the notion of distributing 'Brain Hubs' across the country that would have multidisciplinary teams including allied health professions such as occupational therapy, physiotherapy and social work. This would increase access to dementia services and facilitate better coordination between them. Brain hubs could even be integrated with dementia clinics to streamline the process between diagnosis and treatment. The NDAP also mentions the possibility of incorporating a role for dementia care coordinators informed by international best practice, which would also increase collaboration between services. Scotland's Advanced Dementia Practice Model is an example of international best practice that involves dementia coordination and access to rehabilitation services.

Another way to increase dementia services is to train health and allied health professionals in dementia rehabilitation. OTA acknowledges the training programs available through Dementia Training Australia. There are two other programs the Department may wish to consider which focus on dementia rehabilitation: the COPE program in Australia and the GREAT program in the UK.

Finally, OTA welcomes the acknowledgement in the NDAP that the chronic disease management plan 'may not be sufficient for optimal multidisciplinary care for dementia where there are complex care needs.' OTA members have highlighted that the current Chronic Disease Management Plan rebate is not adequate to support a rehabilitation focussed plan and that the partial rebate for five allied health sessions per year is not sufficient for adequate services. OTA would welcome the opportunity to consult with the Department to improve the Medicare rebates for chronic health issues

Recommendation 1: Integrate the brain hubs outlined in the NDAP with dementia clinics to streamline the process between diagnosis and treatment

Recommendation 2: Modify the Chronic Disease Management Plan rebate to one which supports greater access to services for people living with dementia, and, encourage health professionals to work under this scheme.

Dementia Services to incorporate into the NDAP

An increase in dementia rehabilitation services

Rehabilitation services allow people to 'have as much control as possible over their daily life, to engage in meaningful roles and activities and are able to integrate the changes they experience into a coherent and enduring sense of identity' (Clare, 2017). While rehabilitation is generally thought of in relation to physical rehabilitation after an injury, it is just as relevant for people with cognitive impairments (Clare, 2017). Cognitive rehabilitation strategies for dementia may involve new learning, relearning or the use of compensatory strategies, or a combination of these (Clare, 2017). In early stages of dementia people may want to learn how to cook a meal without getting distracted, or develop strategies to feel confident enough to go out alone. In the more advanced stages of dementia, it might be about maintaining the ability to dress themselves, or enabling them to engage in an enjoyable activity (Clare, 2017).

Cognitive rehabilitation is effective in supporting everyday functioning, reducing disability and institutionalisation (Clare et al., 2010; Clare et al., 2013; Thivierge et al., 2013; Kim, 2015; Amieva et al., 2016).

Moreover, people with dementia have the right to access rehabilitation services. The United Nations Convention on the Rights of Persons with Disabilities outlines the right of people with disability to be able to attain and maintain maximum independence with assistance of comprehensive rehabilitation services (UN, 2006).

Those with dementia and their carers would benefit if the Department was able to create stronger links between diagnosis and treatment, promoting collaboration between all service providers. OTA would be happy to work with the Department to assist with incorporating carer support services and rehabilitation services into the NDAP. For example, OTA is currently part of a research project 'The Right to Rehabilitation for People with Dementia' in collaboration with Monash University.

Recommendation 3: Work with OTA to develop more effective rehabilitation services for people with dementia

The Advanced Dementia Practice Model – Scotland

Scotland's Advanced Dementia Practice Model was proposed by Alzheimer Scotland in 2015, and it was implemented by the Scottish Government in 2018. It sets out how an advanced dementia specialist team works with a dementia practice coordinator for every person with dementia as they progress to the point of requiring community and health care services. The advanced dementia specialist team includes:

- Consultant geriatrician: specialist overview in care of the elderly
- Mental health professionals: promote psychological wellbeing and responses to stress/distress and psychological conditions
- District nurse: input on physical health conditions such as bowel and bladder function and skin integrity

- Allied health professions: occupational therapy for engagement, occupation and environment, physiotherapy for pain management and movement, speech and language therapy for communication and issues with eating and drinking, dietician for nutrition and hydration
- Palliative care specialists: approaches to the management of pain and other distressing symptoms and end of life care.

(Lindsay, 2015, p. 30).

This program is standardised for everyone in Scotland with dementia, so it avoids having several services that are competing for funding and not collaborating in the care of the people with dementia.

With Australia's larger population, landmass and federal system, it may be infeasible to implement the Advanced Dementia Practice Model in Australia as it is in Scotland. However, the range of services and the care coordination in this program would be relevant to the implementation of the NDAP.

Recommendation 4: Consider implementation of aspects of Scotland's Advanced Dementia Practice Model into the NDAP

Dementia Specific Programs

A number of programs currently exist, that support the enablement of people living with dementia to function at the best level possible, remain engaged, and manage everyday activities.

For example, the 'Care of People with Dementia in their Environments (COPE) Program (Australia)' is an occupational therapy and nursing program for people living with dementia and their families. COPE practitioners help the person with dementia to manage their day-to-day activities, and the carer to support the person with dementia to live at home. The program was adapted for the Australian context, from the 'COPE program', developed in the United States, which has proven to reduce dependency, increase engagement in the person with dementia and improve carer wellbeing.

The 'Goal oriented cognitive Rehabilitation in Early-stage Alzheimer's and related dementias: a multi-centre single-blind randomised controlled Trial (GREAT Cognitive Rehabilitation Program) was developed and is used widely in the UK, and enables people living with dementia to function at the best level possible, remain engaged, and manage everyday activities through an individual problem-solving approach.

These programs have been shown to increase function and independence in people with dementia and enhance their engagement in activities, and improve overall wellbeing in caregivers. Despite these positive impacts, these programs are not implemented broadly in Australia.

OTA would welcome the opportunity to support the Department to increase awareness of programs that support people living with dementia, and to implement them more broadly in government funded health organisations, non-government funded health organisations and

private providers. OTA currently offers training in the COPE Program and is investigating options for delivery of the GREAT program, and would be eager to support the implementation of these programs more broadly.

Recommendation 5: Increase the use of the programs such as the COPE and GREAT, to support people living with dementia.

Contact Details

Thank you for the opportunity to provide a submission about the National Dementia Action Plan. Representatives from OTA would gladly meet with the commission to expand on any matters raised in this submission.

For further information, please contact:
Alexandra Eather/Alissa Fotiades
General Manager Government and Stakeholder Relations
Occupational Therapy Australia

Email: policy@otaus.com.au

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