National Dementia Action Plan

Submission by the

Australian Physiotherapy Association

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Australian Physiotherapy Association

The Australian Physiotherapy Association's (APA/Association) vision is that all Australians will have access to quality physiotherapy, when and where required, to optimise health and wellbeing, and that the community recognises the benefit of choosing physiotherapy. The APA is the peak body representing the interests of Australian physiotherapists and their patients. It is a national organisation with state and territory branches and specialty subgroups.

The APA represents more than 31,000 members. The APA corporate structure is one of a company limited by guarantee. The APA is governed by a Board of Directors elected by representatives of all stakeholder groups within the Association.

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Executive Summary

The Australian Physiotherapy Association (APA) welcomes this opportunity to contribute to the Department of Health and state and territory governments National Aged Care Dementia Action Plan (the Plan).

The draft Plan is a welcome step toward improving the diagnosis, care and services for people living with dementia and supporting their carers.

For too long, people who have received a diagnosis of dementia have lacked clear pathways to health and support services and not received the same level of care as others, resulting in a slow progression of the disease.

The focus on memory and cognitive function has, for many, come at the expense of maintaining, or indeed improving, physical health and quality of life for as long as possible.

It is pleasing the Plan recognises the importance of early diagnosis and access to health and support services for people living with dementia. There is scope to more strongly articulate the right to maintaining function, maximising activities and independence throughout the dementia trajectory within the Plan.

There are many challenges within the existing health and aged service landscape faced by people living with dementia. These include:

- physical location
- social and financial circumstances
- pre-existing medical conditions, and
- Pre-existing disability, hearing, vision or physical impairments.

Access to evidence based multidisciplinary health services is fragmented and access to long-term services is hindered by funding gaps.

Dementia-trained physiotherapists can make a valuable contribution to the holistic care of people of all ages living with dementia. However, there is limited professional or financial support in the health and aged care sectors to facilitate learning and career pathways in relation to physiotherapy and dementia.

It is important to recognise and address the reluctance of many who experience symptoms of dementia to seek diagnosis, fearing a loss of control over personal, financial and end-of-life decision-making. Therefore the legal framework – from estate planning to end of life decision-making – must be more strongly integrated in the Plan.

It is important to highlight that people living with dementia face discrimination in many aspects of their lives – including in their ability to make decisions about their own lives. For example, advanced directives do not encompass voluntary assisted dying.

Recommendations

Recommendation 1	State clearly the objective to ensure people living with dementia have the same access to services as those without dementia.
Recommendation 2	Articulate the critical nature of exercise delivered by highly qualified allied health practitioners, such as physiotherapists, in slowing the progression of dementia.
Recommendation 3	Articulate the areas of research required, such as addressing barriers to physical activity participation.
Recommendation 4	Articulate the need for research translation to put emerging research into practice.
Recommendation 5	Invest in specific dementia units in tertiary allied health courses.
Recommendation 6	Invest in dementia education in tertiary physiotherapy courses to ensure a skilled workforce.
Recommendation 6	Include training and mandatory reporting requirements of elder abuse among people living with dementia to recognise signs of elder abuse.
Recommendation 7	Recognise the importance of managing physical function on cognitive function and other co-morbidities and health conditions such as continence.
Recommendation 8	Include a focus on continence, to maintain dignity and quality of life

The role of physiotherapy in overall health and dementia

The physical symptoms of dementia are not widely known in the community but are well-documented in research literature. Balance, coordination and gait are affected as dementia progresses.[1]

Along with changes to visual perception and dual-tasking ability, these physical symptoms of dementia can lead to falls, fractures and hospitalisation.

People living with dementia have a high risk of poor outcomes during hospitalisation, including malnutrition, functional decline, delirium, falls and fractures.[2] Therefore, managing the physical symptoms of dementia in the initial stages of the disease is crucial. Physical

exercise can improve strength, balance, mobility and endurance in people with cognitive impairment and dementia.

Physical exercise can also reduce behavioural and psychological symptoms of dementia and reduce cognitive decline.[3]

Providing optimal healthcare for people living with dementia often requires effective management of multiple health conditions. For example, a UK study found that people living with dementia have on average 4.6 chronic illnesses in addition to their dementia.[4] Physiotherapy is critical to person-centred integrated care that supports people living with dementia to maintain function and prolong independence.

High quality physiotherapy is evidence-based and effective in:

- maintaining and improving mobility;
- falls prevention as well as reducing and minimising harm from falls
- pain management;
- maintaining and improving continence
- behavioural and psychological symptoms of dementia, and
- improving function and optimising comfort.

Physiotherapy's broad scope of practice also includes the management of fatigue, shortness of breath, exercise tolerance, oedema, deconditioning, frailty, contractures, sleep and rest, and skin integrity.

The Australian Physiotherapy Association and Dementia Australia released a joint position statement[5] in July 2022 recognising that physiotherapists play a critical role in the multidisciplinary health care team by maintaining the physical and psychological well-being of people living with dementia. We affirmed the rights of people with dementia to receive timely and ongoing access to physiotherapy services and the need for appropriate funding to support those services.

Physiotherapists can partner with people living with dementia to maximise their physical wellbeing through a wellness and enablement approach. Physiotherapists are experts in prescribing tailored, purposeful and meaningful activities and exercises and can work individually, or as part of a comprehensive inter-disciplinary team, to support the physical and cognitive needs of people living with dementia. Research has shown that physiotherapy

can help improve the quality of life and independence of older Australians, including those living with dementia, by:

- improving motor skills such as gait and balance[6]
- reducing frailty
- slowing cognitive decline, [7]and
- improving cognition, agitation and mood.[8]

Early intervention with physiotherapy is the key to assessing, treating and achieving positive outcomes but studies have shown that access to physiotherapy is not offered in a timely manner for people with dementia.[9]

Falls

Falls are the leading cause of preventable death in older people. Mobility programs led by physiotherapists have been shown to reduce the number of falls in older people including those living with dementia. The Sunbeam Program trial, led by physiotherapist and researcher Dr Jennifer Hewitt, demonstrated the effectiveness of exercise interventions. The results of the trial demonstrated a 55 per cent reduction in falls by people who participated in the exercise program and a projected cost saving of $120 million per year for the Australian health economy.[10]

The *Value of Physiotherapy in Australi*a report[11], commissioned by the APA and produced by The Nous Group, synthesised key clinical research (including the Sunbeam program). It showed the cost benefit of physiotherapy-led exercise in falls prevention among older people. It found a $1,320 net cost benefit of physiotherapy for the older person at risk of falls.

A Cochrane systematic review established that 30% of falls can be prevented with exercise. It also found that exercise interventions reduce the rate of falls (number of falls per person) and risk of falling (proportion of people having one or more falls) in community-dwelling older people.

Pain

One in three people aged over 65 lives with pain[12], much of which can be managed without medication and with the assistance of physiotherapy interventions.

Physiotherapists assess and manage sensory and movement changes that might occur in association with pain, teach pain management techniques, and develop tailored exercise prescription. It is integral to the prevention of chronic pain as early interventions work to prevent pain avoidance behaviours through exercise and education.

Where chronic pain has developed, physiotherapists work as part of a multidisciplinary team to support patients in managing daily activities.[13]

Continence

Urinary incontinence rates are higher in those with dementia (53%), compared to those without dementia (13%).[14] And most people living with dementia are expected to experience continence issues as the disease progresses.

Mobility problems and the inability to transfer have been shown to be greater predictors of incontinence than severity of actual dementia.[15]

There are physical and psychosocial impacts on incontinence on the person living with dementia. They can suffer from skin irritation and pressure ulcers, falls, fractures, and are more predisposed to urinary tract infections. Incontinence in a person with dementia increases their level of dependency and places heavier care burden on caregivers, resulting in earlier institutionalisation.[16]

Tailored physiotherapy interventions, including pelvic floor muscle exercises, fluid management, urgency suppression and bladder training in both men and women can reduce the need for costly surgery and improved quality of life for those suffering from urinary and bowel incontinence.

These interventions have been shown to be successful in people living with dementia. For example, supervised pelvic floor muscle exercises have been found to be a good therapeutic option for improving urinary incontinence in elderly women.[17]

Physiotherapy and translational research

There are two bodies of evidence that we must urgently link and translate into practice.

First, research has shown that physical activity is the key to prevention and delaying the onset of many chronic conditions, including dementia, yet there are barriers for older Australians in exercising.

Physiotherapists are experts in prescribing tailored activities and exercises and should be playing a key role in enabling older Australians to exercise.

Secondly, evidence has also demonstrated that physiotherapy can help improve the quality of life and independence of older Australians by reducing falls, frailty and improving cognitive function.

In people living with dementia, physiotherapy has been found to:

- improve motor skills such as gait and balance
- reduce frailty
- reduce the number of falls
- slow functional decline,
- improve cognition, agitation, mood, and
- improve quality of life and wellbeing.

However, despite this evidence, physiotherapy is not usually sought early despite the knowledge that early intervention is the key to assessing, treating and achieving positive outcomes.

There is a need for more translational research and support to link these compelling sets of studies together and put them into practice among older Australians.

We need to understand:

- the barriers keeping older people from exercising and staving off the onset of chronic conditions, and
- how physiotherapy can improve the quality of life of older Australians and those living with dementia.

National Dementia Action Plan feedback

Overarching	There is no mention of continence in the Plan. Continence issues affect 53% of older people living with dementia compared to 13% of older people without[18] and has significant impacts on people's dignity. A person with dementia is more likely to have accidents, incontinence or difficulties using the toilet than a person of the same age who doesn't have dementia. For some people, incontinence develops because messages between the brain and the bladder or bowel don't work properly. They may not recognise that they have a full bladder or bowel, or be able to control them.[19] There is a lack of intersection with the legal framework in acknowledgment that fear of losing decision-making deters people from seeking diagnosis. The Plan does not address training and mandatory reporting requirements of elder abuse among people living with dementia.
Why do we need an Action Plan?	Opportunities for Improvement, page 5: Suggested additional text italicised: Better, *more affordable, coordinated multidisciplinary* post diagnostic care including support to navigate the Health and Aged Care systems. Suggest further clarification in the following statement : "better dementia data and support to translate dementia research into practice." Does "dementia data" refer to prevalence data or research to support diagnosis, treatment and care?

Groups at higher risk of developing dementia or facing barriers to equitable access	People living in regional, rural and remote areas, page 10: Distance often presents a significant barrier to receiving a diagnosis and accessing the services that people living with dementia and their carers need, such as respite care, transportation, access to allied health and in home supports. Barriers to accessing physiotherapy in rural and remote areas mirror those affecting the medical and care workforces, therefore this must be recognised in the Plan, specifically (insertion italicised): … there are often higher costs to attract, retain and accommodate nurses, *allied health,* such as physiotherapy, and personal care workers in remote areas.
The Immediate Priorities, page 15	The APA suggests the inclusion of wording: People living with dementia have the right to the same access to services as those without dementia and should be supported to do so. Suggested insertion (italicised) in the following dot point: better, *more affordable***,** coordinated *multidisciplinary* post-diagnostic care (*including* immediately following a diagnosis) but noting this need is ongoing.
Objective 1: Tackling stigma and discrimination	Page 19: It could be more explicitly stated that that people living with dementia are often excluded from services and treatments for conditions other than dementia that would be prescribed to others with the same diagnosis, as they are often wrongly thought to not be able to improve or engage in therapy programs. Page 20: Developing a visible symbol, such as a dementia ribbon, to increase visibility and attention during Dementia Action Week. While adding a ribbon to Dementia Action Week could assist in raising community awareness about the dementia, a more meaningful, long lasting, cost efficient and environmentally friendly approach may be raising awareness of people living with dementia and their carers to assist them in understand the healthcare services they can benefit from. Therefore we propose a visible symbol that can be displayed in practices (branded signage) or worn by the practitioners themselves (badges) – as a form of recognition of those with dementia care expertise, including allied health practitioners such as physiotherapists. Page 21: The situation could be improved by: • Accreditation standards for organisations requiring that people living with dementia have the same access to care. • Funding being incentivised to enable those living with dementia have access to allied health to maintain

	independence and wellbeing (for example, through home care packages or Medicare chronic disease plans).
Objective 2: Minimising risk, delaying onset and progression	Page 25: Greater emphasis on the role of physiotherapists in promoting physical activity to slow progression, emphasising the: 1) beneficial impact of physical activity on other risk factors such as hypertension, mood, poor sleep and diabetes 2) improvements through exercise that can be made to mobility and preventing costly falls, and 3) benefits of exercise on slowing cognitive decline, pain management and reducing behavioural symptoms. Page 27: 2.2 People are aware of what they can do to delay the onset and slow the progression, This could be achieved through National audits on the number of people with dementia referred to allied health from cognitive clinics, the number of allied health services included in home care packages (currently about 3 per cent) or provided through Medicare chronic disease management plans. It is also important people with private health cover are not discriminated against and are encouraged to access allied health services. Providing services that can offer access to multidisciplinary allied health which is integrated with existing community programs will allow people with dementia to continue to access options for exercise. This could include that programs andservices are made available for people to delay onset or slow progression, e.g. supported physical activity programs. Page 28: Suggested additional dot point as follows: *Increase in the number of services and programs that support or encourage involvement of people with dementia, or people at risk of dementia, to reduce their risk orslow progression.*
Objective 2: Improving dementia diagnosis and post-diagnostic care and support	Page 29: Ensure that dementia signs are recognised and people are diagnosed as early as possible, helping them to slow progression, maximise independence and their ability to participate in meaningful activities and plan for the future. People are provided with information and are connected to coordinated, inclusive supports immediately following their dementia diagnosis. Page 30: Consider renaming memory clinics to Memory and Thinking clinics to be more inclusive. Consider encouraging multidisciplinary memory and thinking clinics, including allied health, to provide post-diagnostic support and recommendations for the non-cognitive symptoms of dementia. Page 31: Allied health professionals such as physiotherapists have a key role in delaying mental, cognitive and physical decline, as well as assisting people maximise independence and meaningful

	activities through rehabilitation or enablement strategies. There are currently few pathways, organisations or allied health professionals offering such services, particularly in the public system. Post-diagnostic support should address physical function and activity levels. Page 36: Reference to allied health should be made within the following statements: "Developing strategies to promote benefits of early diagnosis to GPs, nurses and *allied health* Page 36 "3.1: include italicised words: "Supporting nurses working in general practice to recognise cognitive change, undertake cognitive screening and communicate with GPs, *allied health* and patients.' 3.3 Post-diagnostic care and support, page 37: Dementia is recognised through chronic disease management plans. This could include referrals for additional allied health and other services, an increase in the total number of funded visits and an increase in rebates to incentivise professionals to provide gap free services. Dementia care planning could be managed through this process with access to specialised dementia practitioners and social work or counselling including specialised services for Aboriginal and Torres Strait Islander peoples and those from the LGBTIQ+ and culturally and linguistically diverse communities. While strengthening the coverage of dementia in the Australian Commission on Safety and Quality in Health Care standards is a positive step, this cannot be undertaken in isolation. An additional dot point is proposed: • Incentivising access to allied health to support people living with dementia to maintain independence and wellbeing. Performance could be audited or measured as described above: For example, national audits on the number of people with dementia referred to allied health from cognitive clinics, physiotherapy included in home care packages or on Medicare chronic disease management plans that include dementia.
Objective 4: Improving treatment, coordination and support along the dementia journey	Page 43:Suggested italicised word change and addition: Chronic Disease Management funded under the Medicare Benefits Schedule items are not always adequate for chronic and/or complex conditions, and accessing private allied health professionals *is* expensive *even with private health insurance rebates*. Lack of reablement options, page 44: Suggested word change italicised: People living with dementia are sometimes *excluded from* reablement options.

	Greater emphasis is required to emphasise the critical need for allied health to maximise function, prevent falls and slow physical and mental decline. It is important to highlight the importance of addressing the lack of clear and understood pathways, affordable programs and skilled workforce that exist. Dementia capacity building should not just be didactic training but a required practical skill building to respond to the behavioural and psychological symptoms of dementia, cognitive and communication issues. Mandatory core competencies on dementia should also be included in undergraduate courses to ensure a qualified health workforce to meet the demand of an ageing population. 4.1 Quality care and ongoing support as a person's needs change. "Exploring the feasibility of having Brain Hubs with multidisciplinary teams established across the country that can work holistically with the person on a range of allied health needs including physiotherapy, occupational therapy and social work." The APA supports this concept, however alternative options need to be developed to supplement this program to ensure access to multidisciplinary care for those living in regional and remote areas who may not be able to access these type of programs, including options for transport. "Developing and implementing early intervention restorative programs that target physical and cognitive function for people diagnosed with mild cognitive impairment and early stage dementia." The APA supports an early intervention restorative approach and programs with a strong awareness component enduring those living with dementia and their carers know how to access the care they need and that general practitioners are also supported to refer to appropriate allied health practitioners, such as physiotherapy, early. "Supporting aged care providers to better understand behaviour support requirements" Aged care providers are able to provide sufficient staffing and services to engage people living with dementia to access meaningful activities and maintain their physical fitness with a component of regular allied health service provision to develop and implement multidisciplinary services aimed at maintaining independence and physical function.
Objective 5: Supporting people caring for those living with dementia	5.2 Respite care, page 52: Respite care must include options for people to engage in activities and reablement programs that can assist with maintaining and improving physical function and independence. Respite should not be viewed as passive but an opportunity for active capacity building through access to allied health services.
Objective 6: Building dementia capability in the workforce	A concerted focus on dementia education in undergraduate physiotherapy courses and professional development in dementia-related training and education will make a significant contribution to

	improving access to high quality physiotherapy services to support people living with dementia in Australia.
Objective 7: Improving dementia data and maximising the impact of dementia research and innovation	The Plan could be more explicit in articulating its approach to research and research translation. Much research excludes people living with dementia, or even older people more generally. Greater investment is required in addressing a range of health conditions such as stroke, persistent pain and musculoskeletal conditions, inclusive of people with dementia. Investment in research on the co-morbidities affecting people living with dementia is required. A focus on engaging clinician researchers in dementia is important. In areas where there is existing an evidence base, such as in the benefits of exercise for dementia prevention and management, investment in translational research to put emerging research into practice is required. Invest in improving the dementia literacy of the health and care workforces to better support the translation and implementation of research into practice.

Conclusion

The APA welcomes the Australian Dementia Action Plan's emphasis on early intervention in the management of dementia. A greater focus on articulating the interdependencies of co-morbidities experienced by many people living with dementia and the critical role that physiotherapy plays in diagnosing, treating and managing these conditions – and preserving the dignity and quality of life of those affected – must be more specifically borne out in the Dementia Action Plan. Developing a skilled care workforce and strong multidisciplinary teams to support the growing number of people diagnosed with dementia, and translating research into practice are also key in ensuring our ageing population, and those with early diagnoses, receive high quality care.

References

[1] Suttanon P, Hill KD, Said CM, Logiudice D, Lautenschlager NT, Dodd KJ. Balance and mobility dysfunction and falls risk in older people with mild to moderate Alzheimer disease. Am J Phys Med Rehabil. 2012 Jan;91(1):12-23. doi:10.1097/PHM.0b013e31823caeea. PMID: 22157433.

[22] Fogg C, Griffiths P, Meredith P, Bridges J. Hospital outcomes of older people with cognitive impairment: An integrative review. Int J Geriatr Psychiatry. 2018 Jun 26;33(9):1177–97. doi: 10.1002/gps.4919. Epub ahead of print. PMID: 29947150; PMCID: PMC6099229

[3] Lam FMH , Huang MZ, Liao LR, Chung RCK, Kwok TCY, Pang MYC (2018) Physical exercise improves strength, balance, mobility, and endurance in people with cognitive impairment and dementia: a systematic review. Journal of Physiotherapy 64: 4–15

[4] Guthrie B, Payne K, Alderson P, McMurdo ME, Mercer SW. Adapting clinical guidelines to take account of multimorbidity. Bmj. 2012 Oct 4;345:e6341

[5] https://australian.physio/sites/default/files/DEMENTIA_AND_PHYSIO_A4_F.pdf

[6] Hewitt J. Progressive Resistance and Balance Training for Falls Prevention in Long-Term Residential Aged Care: A Cluster Randomized Trial of the Sunbeam Program. Journal of the American Medical Directors Association, 2018

[7] Alty J, Farrow M, Lawler K. (2020) Exercise and dementia prevention. Practical Neurology. Jan 21

[8] Brett L, Traynor V, Steapley P. (2016) Effects of physical exercise on health and well-being of individuals living with a dementia in nursing homes: A systematic review. Journal of American Medical Directors Association.;17:104-16

[9] Laver, K.E., Crotty, M., Low, LF. et al. (2020). Rehabilitation for people with dementia: a multi-method study examining knowledge and attitudes. BMC Geriatrics, 20, 531

[10] Hewitt J, Goodall S, Clemson L, Henwood T, Refshauge K. Progressive Resistance and Balance Training for Falls Prevention in Long-Term Residential Aged Care: A Cluster Randomized Trial of the Sunbeam Program. J Am Med Dir Assoc. 2018.

[11] https://australian.physio/sites/default/files/Report_FA_WEB.pdf

[12] Blyth FM et al (2001) “Chronic pain in Australia: a prevalence study” Pain, 89:127-134

[13] Future of Physiotherapy A 10-Year Vision Policy Paper https://australian.physio/sites/default/files/APA_Future_of_Physio_White_Paper_FW.pdf

[14] Campbell A, Reinken J, McCosh L. Incontinence in the elderly: prevalence and prognosis. Age Ageing 1985;14:65–70.

[15] Resnick N, Baumann M, Scott M, et al. Risk factors for incontinence in the nursing home: a multivariate study. Neurourol Urodynam 1988;7:274–6.

[16] Rabins P, Mace N, Lucas M. The impact of dementia on the family. JAMA 1982;248:333–5.

[17] Lee BA, Kim SJ, Choi DK, Kwon O, Na HR, Cho ST. Effects of Pelvic Floor Muscle Exercise on Urinary Incontinence in Elderly Women With Cognitive Impairment. Int Neurourol J. 2017 Dec;21(4):295-301. doi: 10.5213/inj.1734956.478. Epub 2017 Dec 31. PMID: 29298469; PMCID: PMC5756818.

[18] Juliebø-Jones P, Coulthard E, Mallam E, Archer H, Drake MJ. Understanding the Impact of Urinary Incontinence in Persons with Dementia: Development of an Interdisciplinary Service Model. Adv Urol. 2021 Jun 19;2021:9988056. doi: 10.1155/2021/9988056. PMID: 34239557; PMCID: PMC8238624

[19] Toilet problems, continence and dementia, Alzeimer’s Society of UK