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Reablement interventions for community dwelling people living with dementia

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Table of Contents

key messages

- Dementia is one of the leading causes of disability in Australia. People with dementia and their care partners should be enabled to access interventions that address the impact of their disability on their everyday life. Access to these interventions aligns with the World Health Organization Convention on the Rights of Persons with Disabilities.
- Reablement is a person-centred, holistic approach to care regardless of age, capacity, diagnosis or setting. Reablement interventions aim to:
  - enhance, restore or maintain an individual's physical and/or other functioning;
  - enhance, restore or maintain their independence in meaningful daily living activities at their place of residence; and
  - reduce their need for long-term services.

  However, evidence-based reablement interventions targeted to people with dementia are not widely implemented in Australia.
- Dementia is both a medical and social concern. A service model that aids people with dementia and their care partners to access care that is inclusive and addresses their health and social needs is essential. People with dementia, their care partners, health and aged care providers, and state and federal governments should be engaged in co-design of such a service model that addresses the medical and social aspects of the disease. Such a service model will aid people with dementia and their care partners to access care that is inclusive and addresses their needs collectively.
- Support for national evaluation of evidence-based interventions aimed at addressing health and social needs of people with dementia and their care partners should be made available. National evaluation will identify evidence-based interventions that fit within the Australian health and aged care context, and how people with dementia can access these interventions.
- There is poor understanding of dementia and effective interventions. Education about evidence-based interventions, including reablement interventions, should be made available for both for the public and health professionals. Increasing knowledge and understanding of evidence-based interventions will lead to the improved provision of, and access to, interventions and/or services to improve the lives of people living with dementia.

executive summary

Improving quality of life and care provision for people living with dementia is a national priority. Most people with dementia live in the community and rely on family to provide care that enables them to remain at home. Without informal care far more residential care options would be required. People with dementia and their families have requested interventions that optimise function so that they can remain as independent as possible. Such interventions are sometimes called reablement interventions.

This Issues Brief summarises research, government, and non-government documents that have explored the concept of reablement in dementia care; and describes how reablement interventions work to address the needs of people living with dementia and their care partners, as well as how these interventions are, or can be, adopted in the Australian health and aged care context. Recommendations are made to address the identified barriers to including evidence-based reablement interventions for people living with dementia in standard care provision.

First, the rights and care needs of people living with dementia and their care partners are outlined. The cultural attitudes and stigma, specifically among health professionals, towards dementia are then highlighted. Interventions to address dementia related cognitive, physical and functional decline are described before showcasing how and why reablement interventions can and should be applied in dementia care. A detailed case story of the implementation of an evidence-based reablement intervention for people living with dementia in Australia is also provided.

Lastly, the challenges that people with dementia who live at home face when navigating the Australian health and aged care system in order to find services to meet their care needs are outlined. A call is made for the development of a service model that is accessible, cohesive and effective in meeting the needs of people living with dementia.

1 Background

1.1 Dementia in Australia

Dementia is the leading cause of disability in Australians aged 65 years and older (Dementia Australia, 2018). However, dementia is not part of the normal aging process. It represents a collection of symptoms associated with multiple diseases impacting the brain. It is characterised by impairment in memory, language, cognitive skills, perception and personality, impacting an individual's ability to participate in everyday activities (Burns and Iliffe, 2009). In 2021, almost half a million people live with dementia in Australia (Dementia Australia, 2018).

As of yet, there is no cure for dementia and the loss of cognitive and physical function will eventually lead to death (World Health Organisation, 2018). Following diagnosis, people with dementia have been advised to go home and get ready to die (Swaffer, 2015). However, there are several years between diagnosis and death. The average life expectancy following a diagnosis is around 7 to 10 years, although some people live with dementia over 20 years (Brodaty et al., 2012, Fitzpatrick et al., 2005).

Many people with dementia experience discrimination, stigma and social isolation (Mukadam and Livingston, 2012, Batsch and Mittelman, 2012, Alzheimer's Australia, 2017). As a result, they become disengaged from workforce and community participation sooner than the condition requires them to (Clare et al., 2013). The progressive nature of the disease also means that people with dementia are at a greater risk of placement into residential aged care than older people without dementia (Hajek et al., 2015, Luppa et al., 2008). Residential care has been described as an environment of dependency, isolation, and disengagement (Royal Commission into Aged Care Quality and Safety, 2019), negatively impacting the life trajectory of individuals living with dementia.

The ability to continue to live at home, to remain functionally independent (Dementia Alliance International, 2016, Luppa et al., 2008, Productivity Commission, 2015), and to participate in social and recreational activities (Chester et al., 2018) is preferred by people living with dementia; it is also a human right (Dementia Alliance International, 2016).

In 2016, dementia cost Australia over A$14 billion (Brown et al., 2017). Just over half of this cost came from medications, practitioner consultations and hospitalisations. The rest were made up of indirect costs such as lost productivity for people with dementia and their care partners in the workforce (Brown et al., 2017).

The Royal Commission into Aged Care Quality and Safety (2021) report has signalled out dementia care as one of four priority areas for immediate action.

1.1.1 People with young onset dementia

This policy brief focusses on older people (aged 65 years and over) impacted by dementia with the acknowledgement that people with young onset dementia, any form of dementia that has been diagnosed in people aged under 65, also require access to services to address their health and social needs.

1.2 The rights of people living with dementia are not being met

The rights of people living with dementia to participate in healthcare decisions, and receive good quality, timely and accessible health services are not being met.

In 2006, recognising that the human rights of people with a disability are often overlooked, the United Nations adopted the Convention on the Rights of People with Disabilities (CRPD). Subsequently, in 2008, Australia committed to protect and respect the convention (Attorney-General's Department, n.d).

Dementia was included in the 2019 United Nations (UN) Special Rapporteur on the rights of persons with disabilities; a UN General Assembly report on older persons with disabilities (Devandas-Aguilar, 2019). The report focussed on the connection between ageing and disability and made a series of recommendations to ensure that member states, including Australia, enact laws which (Devandas-Aguilar, 2019):

- prohibit discrimination based on age or disability
- establish rights-based community support
- improve the accessibility of the physical environment
- guarantee access to justice and
- promote participation in decision-making.

In Australia, breaches of these recommendations have been highlighted by the Royal Commission into Aged Care Quality and Safety (2019, 2021), including a series of systematic issues related to undermining the rights of older Australians, and people living with dementia.

People aged 65 and over diagnosed with dementia rely on aged care services and facilities which have been designed to address ageing related needs, not disability. Yet, people with dementia have complex care needs which increase as the disease progresses. People living with dementia should be supported to find suitable strategies to cope with their disability (Dementia Alliance International, 2016, Van Der Roest et al., 2007). A care system that ensures access to reasonable and necessary disability supports to meet the needs of people who live with dementia is required. As such, the definition of dementia should be reframed to include the concept of disability (which is already done in other neurodegenerative conditions such as Huntington's disease or motor neurone disease).

Dementia as a disability is further discussed in Appendix A.

1.3 Care partners of people living with dementia

Almost 75% of Australians with dementia live in the community and rely on informal care provided by the family or friends to be able to remain living at home, instead of moving to residential aged care (Michalowsky et al., 2016, Brown et al., 2017, Mittelman et al., 2006). There are approximately 200,000 informal care partners of people with dementia in Australia and they are almost twice as likely as any other co-resident primary care partner (that is, care partner of someone with a condition other than dementia) to provide 40 or more hours of care per week (81% versus 42%) (AIHW, 2012, Brown et al., 2017). Nearly half of care partners are employed in the workforce and are required to reduce work hours due to caregiving commitments (Brown et al., 2017). This leads to higher economic impact on society due to indirect costs such as forgone earnings. Contemporary data on the numbers of informal care partners of people with dementia is lacking.

The complex needs of the person with dementia and the gradual increase in dependency can significantly impact on the health and lifestyle of their care partner. For example, informal care partners have the responsibility to address and manage changes in behaviour, to ensure a safe home environment, and to engage the person with dementia in everyday living activities (Edwards, 2015, Jennings et al., 2015). Carer stress is common which can lead to subsequent reduction or cessation of care provision, resulting in a move to residential care for the person with dementia (Hughes et al., 2014, Gaugler et al., 2011). For some people with dementia, informal care is the only form of care they receive (SGRGSP, 2018). Without informal care, an increased number of residential care options would be required as there would be no sufficient supports for people with dementia to continue live in the community (Gaugler et al., 2009, Gallagher et al., 2011).

In 2018, the Productivity Commission identified three high quality studies demonstrating the significant effects of intervention programs that support care partners in their role to help delay or prevent entry into residential aged care for the person with dementia (SCRGSP, 2018). These interventions consisted of either counselling (Gaugler et al., 2013, Mittelman et al., 2006) or case management (Chien and Lee, 2011). However, it was found that none of them were “appropriate for adoption” in Australia for the purpose of delaying or preventing entry into residential care (SCRGSP, 2018). In addition, none of the highlighted interventions adopted an approach which included addressing an individual’s (with dementia) and their care partner’s needs related to cognitive, physical and functional decline associated with dementia.

Support for care partners has been identified in the 2021 Aged Care Royal Commission as an area of needing attention (Appendix B, Recommendation No 42). However, the support for informal care partners needs to extend beyond assessment of and access to respite care. For example, a review synthesising research on respite care for care partners of people with dementia found that while day care services can be effective in decreasing caregiver burden and behavioural changes in the care recipient, they can also hasten time to residential aged care admission (Vandepitte et al., 2016b).

Other research that has synthesised evidence of interventions aimed at care partners of people living with dementia has found that psychoeducational interventions can lead to positive outcomes for care partners and delay entry to residential aged care for care recipients (Vandepitte et al., 2016a). Cognitive behavioural therapy has also shown to decrease dysfunctional thoughts among care partners, and occupational therapy can decrease behavioural changes in people with dementia and improve self-efficacy of care partners (Vandepitte et al., 2016a, Laver, 2016, Bennett et al., 2019). Overall, interventions that are tailored to individual needs appear to produce better outcomes for both people with dementia and their care partners (Laver et al., 2014, Laver et al., 2017).

The Australian Government should ensure that informal care partners are appropriately supported. Care partners should be enabled access to preventative, rather than reactive, care support at an early stage of dementia (immediately after diagnosis). As such, we need interventions that are psychoeducational in nature and support care partners of people living with dementia to understand the disease and cope with related changes in behaviour, to manage stress, to increase their caregiving skills and sense of self-efficacy. Care partners should also be linked with appropriate supports and services, such as occupational therapy. These interventions can assist in keeping people with dementia living in their homes and out of residential aged care for longer, and subsequently help reduce health and social care impact of dementia in Australia.

2 Attitudes towards dementia are harmful and hinder opportunities for care

2.1 Addressing stigma and misconceptions about dementia

Stigma towards people with dementia is well documented among general public, family members, long-term care workers, nurses and general practitioners (Herrmann et al., 2018, Alzheimer's Australia, 2017, Batsch and Mittelman, 2012, Mukadam and Livingston, 2012, Werner and Giveon, 2008).

In Australia, the concept that people with dementia could benefit from interventions that are rehabilitative and provide meaningful outcomes has been questioned by health professionals (Cations et al., 2020); with some care providers voicing a belief that nothing can be done to help individuals living with dementia (Batsch and Mittelman, 2012, Goodwin and Allan, 2018). This can create barriers to appropriate care, and lead to poor policy formation and misdirected funding.

For example, while people with dementia can benefit from rehabilitative interventions similarly to older people without dementia (Resnick et al., 2016, Seitz et al., 2016) these interventions are not a part of the usual treatment pathway for dementia (Cations et al., 2018a). Interviews with 16 healthcare professionals from a variety of service settings and professional backgrounds (predominantly from South Australia) have also indicated a belief that rehabilitation outcomes achievable for people with dementia are not fulfilling (for health professionals), and such interventions or programs for people with dementia are rarely seen as worthy of the investment of scarce resources (such as time or money) (Cations et al., 2020).

Other issues identified as contributing to stigma towards people with dementia include (Werner and Giveon, 2008, Petrazzuoli et al., 2017, Gove et al., 2016, Vernooij-Dassen et al., 2005, Aminzadeh et al., 2012):

- limited insight into the therapeutic benefits of early dementia diagnosis
- little attention that is given to assessment and recognition of dementia symptoms
- feelings of helplessness
- concern of the harmful impact that providing a diagnosis of dementia can have on patients and their families and
- reluctance to communicate a dementia diagnosis.

The focus of diagnostic and post-diagnostic care should therefore be on the benefits of timely diagnosis and how to build on the capabilities of people living with dementia. More attention should be paid on assessments. For example, by incorporating a cognitive assessment, such as the Mini Mental Status examination (MMSE), in routine health check of anyone aged 65 and over.

The MMSE is commonly used for checking signs of cognitive impairment and can be used to determine whether cognition is declining. Early identification of signs related to cognitive impairment would enable people to acquire relevant information and seek timely access to support services, plan for the future, engage in cognitive health promotion activities, and access treatments that may improve their quality of life (Batsch and Mittelman, 2012, Petrazzuoli et al., 2017, Werner and Giveon, 2008).

2.2 Prioritising dementia education

2.2.1 Knowledge and skills needed for dementia care are lacking

Interventions to support people living with dementia require specialist dementia knowledge, however the extent to which health professionals have been educated about dementia varies (Hsu et al., 2005, Robinson et al., 2014, Smyth et al., 2013). For example, a survey with over 100 nurses in Queensland showed limited understanding of the disease progression and underlying pathology, and therefore lack of readiness to work with people with dementia (Hsu et al., 2005). Similar results were reported in another survey conducted with almost 300 residential aged care workers in Victoria, Tasmania and Western Australia (Robinson et al., 2014). In particular, training of the dementia workforce in evidence-based interventions is rarely provided in universities or workplaces (Hodgson and Gitlin, 2021, Royal Commission into Aged Care Quality and Safety, 2021). This has resulted in people diagnosed with dementia receiving inconsistent care, with inconsistent outcomes (Royal Commission into Aged Care Quality and Safety, 2021).

A national survey of over 200 Australian health professionals found that the workforce want improved education regarding evidence-based non-pharmaceutical interventions that address the needs of people living with dementia (Annear, 2020). This issue was also highlighted by the 2021 Royal Commission into Aged Care Quality and Safety, in which several recommendations were made relating to improving healthcare workforce education; and more specifically that all aged care workers in direct contact with people seeking or receiving service undertake regular training about dementia (Appendix B: recommendations No 80, No 81 and No 82).

Higher education institutions also play a significant role in the preparation of the future health and aged care workforce. Yet, dementia education delivery within existing primary care (medicine, nursing and allied health) programs is lacking (Traynor et al., 2011). For example, a study that mapped nursing curricula content from several countries, including Australia, revealed selective inclusion of dementia education in undergraduate programs (Traynor et al., 2011).

Tertiary institutions offering programs that train Australia's future healthcare workforce should consider including dementia specific content in their in their curriculum. For this to occur, working with people with dementia could be added as an endorsement for approved area of practice as per section 98 of the Health Practitioner Regulation National Law (The State of Queensland, n.d.)

Continuing professional development courses about dementia exist in Australia (for example Eccleston et al., 2019, Flinders University, n.d.). While some courses are aimed at the health professionals only, others are publicly available for anyone interested in learning more about the disease. These courses can be used to enhance healthcare professionals' knowledge about treatment and interventions available for dementia, as well as the role of different health professionals in supporting people living with dementia. These courses should be utilised, and participation should be encouraged, if not mandated, for anyone working with people with dementia. Transparency around the Government allocated budget to upskill the existing workforce and providing training for new aged care workforce should be increased, so that organisations know which bursaries are available to cover the cost of staff participation in fee-based courses related to dementia (see also Appendix B, recommendation No 114,).

2.2.2 Public awareness and the health and social needs of people with dementia

The general population in Australia has limited knowledge of reducing the risk of dementia (Garvey et al., 2011, Smith et al., 2014), or of the treatments available for people living with dementia (Rahja et al., 2018b).

Despite a 2009 survey of 2000 Australians finding that most participants not only recognised symptoms of dementia, but also knew that dementia risk can be reduced (Low and Anstey, 2009), results from more recent surveys have been less encouraging. In 2014, a survey of 1000 participants showed that less than half of the participants believed that the risk of dementia could be reduced (Smith et al., 2014). In 2018, an online survey of 1000 Australians conducted by Flinders University showed that more than half could not name any treatments that improved outcomes for people with dementia (Rahja et al., 2018b). Of the treatments that were identified, aspects related to social support and participation were only named by 4% of the surveyed participants. When presented with treatments that have frequently shown to be effective in research studies, less than half of the surveyed participants considered these very likely to be effective (Rahja et al., 2018b).

This suggests that following a diagnosis of dementia, people may not be aware of the existence of care interventions that can address their needs, leading to insufficient support for themselves and their care partner. For example, formal care for dementia is most often sought at a point of crises, such as during hospitalisation following a fall, or when there has been an increase in changes in behaviours that are not understood by informal care partners (Vroomen et al., 2013). This means that there are fewer opportunities within the community to access preventative interventions as care is not accessed at the time of initial symptom presentation or dementia diagnosis.

2.2.3 Reducing stigma

Stigma exists in the absence of accurate understanding of dementia, which contributes to social isolation and emotional distress for people with dementia and their care partners (Cations et al., 2018b). In order to reduce this stigma and to improve quality of care for people with dementia, there is a need to raise the public's awareness regarding available effective treatments (Rimmer et al., 2005).

Knowledge about available treatments and their effectiveness can lead to an individual's increased ability to seek appropriate support (Hochbaum, 1959, Hochbaum et al., 1952). Within dementia care, increased knowledge can reduce care partner burden (Jorm, 2012), stigma (Mukadam and Livingston, 2012), and the social impact of dementia (World Health Organization, 2012). For example, reablement type interventions have shown to be cost effective ways of improving person's daily functioning, mobility and independence (Jones et al., 2012, Knapp et al., 2013, Rahja et al., 2018a).

Research studies aimed at industry and academics have shown that early intervention and investing in prevention, rather than managing risk, is economically beneficial (Lewin et al., 2013b, Lewin et al., 2014, Rahja et al., 2020b). Awareness of this benefit is limited among the general public.

3 Interventions to address cognitive, physical, and functional decline of dementia are not widely implemented in Australia

3.1 Components of effective dementia care

In Australia, dementia care fails to meet the needs of individuals living with dementia (Royal Commission into Aged Care Quality and Safety, 2021). The 2021 Royal Commissions into Aged Care Quality and Safety, has attributed this failure to:

- limited training of health professionals in evidence-based programs targeted specifically for people with dementia
- limited understanding that both people with dementia and their care partners can improve in function and wellbeing, and
- a health system that has focussed on assessment and case management rather than treatment.

In 2014, when the Government announced $200 million for the Boosting Dementia Research Initiative (Commonwealth of Australia, 2014), the National Health and Medical Research Council (NHMRC) established the National Institute for Dementia Research (NNIDR) to operate until 2020. The NHMRC NNIDR was an umbrella institute that focussed on translating dementia research evidence to practice with the vision to create improved outcomes for people with dementia, their care partners, and the Australian community (NHMRC National Institute for Dementia Research, 2017). Within the NHMRC NNIDR a special interest group was formed in rehabilitation and dementia. The special interest group has explored models of service delivery for people with dementia in Australia and made recommendations for the future about what an efficient model may look like in terms of meeting the needs of people with dementia and their care partners (NHMRC National Institute for Dementia Research Special Interest Group in Rehabilitation Dementia (NIDRSIGRD), 2021). These recommendations include:

- having an overarching objective to maintain positive health and wellbeing of people with dementia, their care partners and families

- recognising dementia as a disability, consistent with the World Health Organization Convention on the Rights of Persons with Disabilities, and promoting autonomy, social participation and rehabilitation
- considering the cognitive disability of people with dementia in accessing support and being a partner (along with their families) in planning care through supported decision making
- delivering services by a multidisciplinary workforce who have knowledge and skills around dementia
- being accessible for all people with dementia and their care partners
- being ongoing, cost-effective and economically sustainable
- being needs-based, not capped according to central budgets
- being integrated for seamless experience for people with dementia and their care partners, within and across primary, acute and subacute health care, aged care and social services,
- and being evidence-based.

Care and services that follow these principles are more likely to enable people with dementia to have their needs met (Royal Commission into Aged Care Quality and Safety, 2021) (see Appendix B, recommendations No 35, No 36 and No 118).

3.1.1 Promoting independence and quality of life after diagnosis

People with dementia experience cognitive, physical and functional limitations (World Health Organization, 2012). Yet, in Australia, intervention programs that allow people with dementia to remain living at home, to remain functionally independent and to engage with their communities are lacking (Clemson et al., 2018, Maslow, 2012).

Care interventions that adopt a philosophy and positive focus around the possibilities that people have for living well with dementia, and what people with dementia can do given appropriate support, are referred to as reablement interventions (Poulos et al., 2017). Reablement interventions have the potential to equip people with dementia (and their carers) with the skills (Clare, 2016):

- to remain living at home, and
- to remain functionally independent and to engage in their communities.

Reablement interventions have the potential to keep people living at home for as long as possible, reducing the impact of dementia to the health and aged care system (Lewin et al., 2013b, Rahja et al., 2020b).

Reablement interventions have yet to be adopted in standard care practices in Australia, despite being recommended for adoption by the Royal Commission (Royal Commission into Aged Care Quality and Safety, 2021), aged care quality standards (Aged Care Quality and Safety Commission, 2020), and the Productivity Commission (Productivity Commission, 2011). They are within clinical practice guidelines for care of people with dementia (Guideline Adaptation Committee, 2016) and fit within the current aged care funding opportunities in the community, as shown in a 2018 implementation research study conducted in New South Wales and South Australia (Clemson et al., 2018, Clemson et al., 2020, Rahja et al., 2020b). Reablement interventions for people with dementia differ from standard reablement interventions by including a focus on the care recipient and their (informal) care partner (for example, family or friend - collectively known as ‘dyad’) (Poulos et al., 2017) rather than on the care recipient only.

What is reablement in dementia care?

Reablement is a person-centred, holistic approach that helps people learn or relearn the skills necessary for everyday living which have been lost through deterioration in health and/or increased support needs (Poulos et al., 2017).

Reablement aims to maintain an individual’s independence at their place of residence and to reduce their need for long-term services. Reablement interventions consist of multiple visits and are delivered by a trained and coordinated interdisciplinary team, including allied health (Metzelthin et al., 2020).

The care approach includes an initial comprehensive assessment followed by regular re-assessments and the development of goal-oriented support plans (see Table 1). Reablement interventions support an individual to achieve their goals, if applicable, through participation in daily activities, home modifications and assistive devices as well as involvement of their social network. Reablement is an inclusive approach irrespective of age, capacity, diagnosis or setting (Metzelthin et al., 2020).

Reablement interventions in dementia care consider (Poulos et al., 2017, Clare, 2016):

- cognition
- engagement in activity and/or social participation
- behavioural or psychological symptoms of dementia such as repetitive questioning wandering, agitation, apathy, depression, motivation, and sleep disturbance, and
- difficulties experienced with communication.

Interventions engage a range of evidence-based strategies that work towards achieving goals related to, for example, areas of the person’s impairment or ability participate in everyday or social activities. Strategies may include approaches such as:

- learning or relearning skills
- modifying activities or ways of doing activities
- using compensatory methods such as adapting the environment or using assistive technologies
- understanding and addressing changes in behaviours, or physical activities and training.

Research studies have shown that the Western Australian restorative home care service, known as the Home Independence Program (HIP), is effective both in terms of individual outcomes related to participation in activities of daily living, quality of life and physical function, and reduction in use of home and health care services (Lewin et al., 2013b, Lewin et al., 2013a, Lewin and Vandermeulen, 2010, Lewin et al., 2014). The HIP is delivered by a trained multidisciplinary team consisting of occupational therapists, physiotherapists and nurses who work collaboratively with one team member acting as the Care Manager for each client.

It is important to recognise that reablement interventions for people with dementia differ from reablement programs that are being recognised in current policies targeted to older people more broadly (International Federation on Ageing, 2016). The standard components of a reablement intervention can be seen in Table 1.

Table 1: Standard components of reablement intervention.

Component	Steps incuded in the component
Initial assessment	Baseline assessment of person's intrinsic and functional ability and environment.
Goal setting	Goal setting is completed together with person and can be guided by different goal setting apporaches (such as strutcured interviews). A personalised reablement intervention is planned with the person (and their support network as appropriate). A goal achievement plan is developed in consultation with the person (their support network and/or their GP, where apporpriate) to achieve the set goals. The reablement intervention coordinator will link the person with relevant health professionals to work towards the achievement of the set goals.
Reablement intervention	Number of consultations with personalised intervention that is focused on achieving the set activity or participation-based goals. Each goal is addressed systematically by using a mix of strategies such as: • practicing activities • identifying strategies to compensate for changes • working with the person's care partner or network (education, skills building) • modifying the home environment. New devices or technologies can be prescribed to assist with goal achievement and/or independence, where appropriate.
Review of goals	Review of goals and their achievment. Future planning with person (and person's network as appropriate) to sustain lerned strategies. Summary of intervention is sent to GP and/or specialist that will include stratgies for longer-term sustainbility of learned knowledge and skills.

Dementia is an independent factor from other illness or injury that benefits from a reablement approach aimed at increasing or maintaining independence in meaningful activities of daily living (International Federation on Ageing, 2016, Poulos et al., 2017).

Research studies of reablement programs in aged care have typically excluded people living with dementia. However, systematic reviews of interventions that use reablement-type approaches for dementia show that functional decline associated with the condition can be delayed through occupational therapy (see Appendix C for more detail about occupational therapy) (Bennett et al., 2019) or tailored multi-component interventions (interventions that combine two or more treatment strategies) (McLaren et al., 2013, Scott et al., 2019).

Slowing down functional decline means that people with dementia are more likely to be able to participate and complete everyday living activities and require less help to remain living at home. More specifically, interventions that improve the physical home environment (for example by including railing, adjusting lighting or decluttering), the ability of the person with dementia to participate in everyday living activities, and the knowledge and skills of their (informal) care partner have been found to be the most effective in delaying functional decline associated with dementia (Laver, 2016).

Of the psychosocial interventions aimed at reducing behaviours of concern and psychological difficulties related to dementia, interventions that are comprised of multiple components over a set length of time and in the person's home, have been shown to be most effective (Brodaty and Arasaratnam, 2012, Laver et al., 2014, Bennett et al., 2019, Livingston et al., 2020). These interventions are tailored to meet an individual's needs and engage carer partners of people with dementia.

3.1.2 Investing in allied health services

Reablement interventions for people with dementia are not widely implemented in Australia (Maslow, 2012, Clemson et al., 2020, Bennett et al., 2020). As a consequence of the limited availability of services or funding, not all people who need it can access high quality allied health support after a diagnosis of dementia (Royal Commission into Aged Care Quality and Safety, 2021). This is regardless of the evidence described in reviews of research studies (Bennett et al., 2019, Laver, 2016, Laver et al., 2014, McLaren et al., 2013, Scott et al., 2019) that support the use of allied health interventions in maintaining or enhancing a person physical or cognitive function. This means that people with dementia do not get access to services that help maintain or enhance their function and health.

The 2021 Royal Commission into Aged Care Quality and Safety has made several recommendations to support people with dementia to access care that addresses their needs and values (Appendix B: recommendations No 3, No 35, No 36). Central to these recommendations is the concept that aged care should adopt a reablement and rehabilitative approach; and that care accessed at home should include allied health input that works to restore and maintain a person's physical and mental health to the highest level possible, for as long as possible, in order to maximise their independence and autonomy. This type of care will enable people with dementia to continue to live a meaningful life and be less isolated.

The provision of allied health services to maintain or enhance cognitive and physical function for people with dementia should be effectively embedded into aged care policy. This could be done, for example, by increasing funding alowances to access such services, an by promoting access to and increasing availability of such services.

3.2 Rehabilitative and reablement interventions benefit people with dementia

Despite doubt around the ability of people with dementia to engage in intervention programs that adopt rehabilitative approaches (Cations et al., 2020), several strategies can be effectively used to involve this population group in addressing their own health and social needs. This includes interventions that adopt rehabilitative approaches to address activity and function related concerns. behavioural changes related to dementia, and care partner wellbeing. These approaches have been designed and evaluated in numerous research studies which show that people with dementia can participate in intervention programs that ask them to set goals and work towards addressing the physical, cognitive and/or functional difficulties they experience due to their dementia (Allan et al., 2019, Chew et al., 2015, Clare et al., 2011, Clare et al., 2019a, Clare et al., 2019b, Clemson et al., 2020, Gitlin et al., 2010, Jennings et al., 2018, O'Sullivan et al., 2015, Resnick et al., 2016, Seitz et al., 2016). Informal care partners can also participate in such programs and gain knowledge and skills that help them continue in their caregiving roles (Chenoweth et al., 2016, Clemson et al., 2020, Gitlin et al., 2010, Rahja et al., 2020a).

Engaging people with dementia in these types of interventions is more effective when health professionals delivering the programs have knowledge, skills and/or experience in working with people with dementia (Allan et al., 2019, Clare et al., 2019a, Clare et al., 2019b). This has been shown, for example, in, a randomised controlled trial of 475 participants with dementia and mild to moderate cognitive impairment from eight different National Health Service (NHS) centres in the United Kingdom. The intervention in this trial included weekly home visits by a specially trained health professional for people with early-stage Alzheimer’s and related dementias and was shown to improve function in the specific areas of concern identified through goal-setting by the participants (Clare et al., 2019a, Clare et al., 2019b). With a willingness-to-pay value of £2500 and above for improvement in the participants’ goal attainment measure, the intervention was also shown to be cost effective from the health and social care, and societal perspectives (Clare et al., 2019a).

In Italy, a small study (22 people) of a multidisciplinary team-delivered home care assistance program in people with mild-to-moderate Alzheimer's type dementia found that participation in daily living activities and behavioural and psychological symptoms was improved (Carbone et al., 2013). The intervention program lasted for up to three months and consisted of three sessions per week, each lasting for six hours (Carbone et al., 2013) making it difficult to implement in the Australian health and aged care context.

In Australia, the Interdisciplinary Home-bAsed Reablement Program (I-HARP) (Jeon et al., 2017a, Jeon et al., 2017b, Jeon et al., 2020) has been adapted from a reablement program aimed to reduce disability in older adults who are cognitively intact (Szanton et al., 2014, Szanton et al., 2011). A pilot randomised controlled trial was completed with 18 participants to determine the potential impact of I-HARP on the participants’ everyday living activities, mobility and health-related quality of life, mood, and care partner burden and quality of life. Initial results from the I-HARP study have demonstrated slowing down of functional decline and improvements in functional independence and quality of life for people with dementia, as well as improved care partner wellbeing (Jeon et al., 2020).

3.2.1 The Care of Persons with dementia in their Environments (COPE) Intervention

In the United States, the Care Of Persons with dementia in their Environments (COPE) intervention (Gitlin et al., 2010) has been shown to address many of the fundamental elements of dementia care: improving physical health and function, engaging the person with dementia in daily activities, maintaining quality of life, and supporting care partners (Prince et al., 2009, Gitlin et al., 2010). Evaluation through a randomised controlled study of over 200 people with dementia and their care partners found COPE to improve functional independence and participation in everyday living activities of people with dementia and improve their care partner wellbeing (Gitlin et al., 2010).

In Australia, the NHMRC Cognitive Decline Partnership Centre funded 'the COPE Australia project' (Clemson et al., 2018, Clemson et al., 2020) through the $200 Boosting Dementia Research Initiative (Commonwealth of Australia, 2014). The COPE intervention was subsequently implemented in 104 community dwelling people living with dementia in Australia (Clemson et al., 2020). Participant specific outcomes showed that in addition to improved care partner wellbeing, COPE helped improve the care partners' confidence in continuing providing care at home, for example through learning problem solving skills and coping with changes in behaviours (Clemson et al., 2020, Rahja et al., 2020a). As in the United states trial, the people with dementia showed increased engagement in activities following participation in COPE.

The delivery of COPE using telehealth modalities has been assessed in 63 people with mild-to-moderate dementia and their care partners (Laver et al., 2020), showing that it is possible to adapt and offer the intervention using telehealth delivery (Laver et al., 2020). The study found no differences in the clinical outcomes for the participants and that using telehealth required less resources than home visits (Laver et al., 2020).

Social and economic benefits of COPE

The COPE intervention (www.copeprogram.com.au) is the first of its kind to be implemented in Australia (Appendix D). With 17 government, aged care and private practice organisations initially providing services for community dwelling people with dementia, the intervention has been deployed across both metropolitan and regional areas, and across different service contexts, including government funded geriatric community services, short-term transitional care programs or Commonwealth Home Support Programs, non-government aged care organisations and private providers through Home Care Packages or Veteran's Affairs allowances) (Clemson et al., 2020)[1]. Participants (people with dementia and their carers) across all geographical areas and regardless of which service context they used to access the intervention, have reported positive experiences and outcomes (Rahja et al., 2020a).

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[1] As of June 2021, over 100 therapists across Australia have been trained to deliver COPE.

Cost-benefit evaluation has shown that delivering COPE through existing services could provide economic gains to the Australian health and social care system of approximately A$8.1 million (Rahja et al., 2020b). This estimate includes program staff attrition (see Appendix D) (Rahja et al., 2020b).

However, analysis also showed that program costs are disproportionately carried by the person with dementia and their family. The ability of families to access funding support to access the program (or other reablement programs) will be a barrier to uptake.

Health funding bodies, including the Australian Government, should support the uptake and inclusion of reablement programs in standard care provision for people with dementia and their care partners.

4 Access to reablement interventions for people with dementia is limited

4.1 The challenges of accessing appropriate services

People with dementia who live in the community are expected to know their own health care needs, choose their own service providers, and inform the provider of their service preferences (Department of Health Australia, 2012). However, their experiences of cognitive, physical, and/or sensory decline can severely impact on their capacity to manage and carry out informed choices of care providers on their own. For example, many people with dementia may not be aware that they have care and/ or service provider choices (Henderson and Willis, 2020) and familiarity around the services available is lacking (Gill et al., 2018).

In Australia, health related services to people with dementia who live at home are delivered via state Local Health Services, non-government organisations, or private practitioners (Commonwealth of Australia, 2013). The introduction of Consumer Directed Care in 2012 (Department of Health Australia, 2012) has seen Australians with dementia aged 65 and older shift to Home Care Packages, delivered through My Aged Care, as a way of accessing affordable home-based care services that are based on independently assessed care needs (Department of Health Australia, 2012).

While, Home Care Packages have increased ‘choice’ by providing consumers, including people with dementia, with increased care and service provider options (Department of Health Australia, 2012), it has also created additional barriers for people with dementia. For example, many are unable to choose the care they wish to receive, have sufficient funds to choose the optimum care for themselves, know what their care includes, and have the capacity to change their mind if they are not happy with the choices that they have made or the care that they have received (Henderson and Willis, 2020). This issue should receive greater recognition from government.

A small study of 14 Home Care Package users from New South Wales and South Australia has highlighted the fact that services accessed by people using Home Care Packages are based on what providers can offer, not based on their needs or preferences (Gill et al., 2018). In this regard, the care clients receive may not be equitable and sufficient to their level of need. For example, preventative care that builds on a person’s cognitive and functional capacities and adopts an enabling rather than risk management approach is rarely accessed (Healthdirect Australia, 2018, Royal Commission into Aged Care Quality and Safety, 2021).

It is unclear how many people with dementia are currently waiting for Home Care Packages to be able to access care at home. However, wait times to access these packages have taken up to 2 years or longer (Department of Health, 2020). Therefore, it is probable that people with higher level care needs, for example, people with dementia, may be required to wait over 12 months to access the level of package appropriate to their needs (Table 2). Consequently, the progressive nature of the disease means that opportunities for treatment will be lost and personal and care partner burden will be increased.

Table 1. Approximate wait time by Home Care Package (HCP) level. Retrieved from Department of Health (2020)

HCP level	First HCP assignment	Time to first HCP	Time to approved HCP
Level 1	Level 1	3-6 months	3-6 months
Level 2	Level 1	3-6 months	12+ months
Level 3	Level 1	3-6 months	12+ months
Level 4	Level 2	12+ months	12+ months

The collection and reporting of data concerning people with dementia who are receiving and/ or awaiting to access their allocated Home Care Packages should be prioritised. This could be achieved by including additional questions in the existing ABS Survey of Disability, Ageing and Carers regarding access and wait times for services delivered through Home Care Packages

As of June 2020, almost 103,000 older people were waiting for a Home Care Package. While the Government has announced an additional 80 000 Home Care Packages (up to 2023) in the 2021-22 budget (https://budget.gov.au/) more packages should be made available for older Australians, including those living with dementia; and the waitlists for these packages should be cleared.

The Government should consider funding options that embed personal care and home care in routine services and enable increased access to therapeutic services, such as allied health, for consumers accessing Home Care Packages.

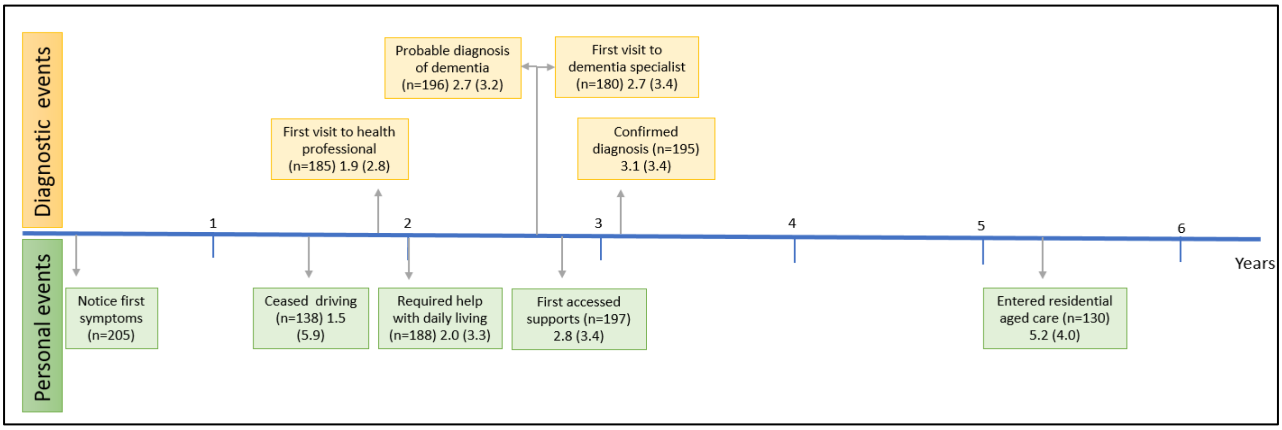
4.2 Diagnostic and post-diagnostic dementia services are fragmented

Diagnostic and post-diagnostic dementia services vary across Australia (Ng and Ward, 2019), creating inequitable care opportunities for this vulnerable population. Diagnosis and initial management of dementia can occur in general practice, hospitals, memory clinics, private specialist practices, community and care institutions where service accessibility, diagnostic processes, and effectiveness in care within and across these settings differ (Australian Institute of Health and Welfare, 2012, NHMRC NIDRSIGRD, 2021). The diagnostic settings in Australia, including their roles, strengths and limitations are described in more detail in Appendix E.

General Practitioners (GPs) are in a key position to identify symptoms, diagnose dementia, organise specialist dementia supports and continue with disease management (Iliffe et al., 2009, Speechly et al., 2008, Ng and Ward, 2019). However, dementia knowledge among GPs is limited, leaving the diagnostic and post-diagnostic care pathways for dementia fragmented (Robinson et al., 2014, Hsu et al., 2005, Smyth et al., 2013, Ng and Ward, 2019) and resulting in lost opportunities for timely medical and social interventions for people living with dementia and their care partners. In addition, it has been reported that GPs are often hesitant to suggest dementia as a possible diagnosis. This is due to the uncertainty or the stigma associated with the disease (Phillips et al., 2011).

There is also a belief among GPs that diagnosis or further tests would not change patient care management (Ahmad et al., 2010, van Hout et al., 2007). In contrast, specialists (such as geriatricians or neurologist) are more confident and have increased ability to diagnose dementia compared with GPs, however they are more difficult and costly to access (Ng and Ward, 2019). Data from 2008 has shown that there may be a delay of almost two years from initial symptoms before a person presents to a health professional; and almost 3 years from initial symptoms before a probable first diagnosis of dementia is made (Figure 1) (Speechly et al., 2008). While contemporary Australian data is lacking, work from Norway suggests that these timelines are still appropriate (Helvik et al., 2018).

Figure 1. Timeline representing personal and diagnostic events leading to dementia diagnosis. Adjusted from Speechly et al. (2008).



Differences in post-diagnostic care across care settings results in variable access to specialised medical and multidisciplinary care teams that are essential for effective dementia care. For example, research around services and care provision in Australia indicate that only some memory clinics offer longer-term follow-up (Lin et al., 2020, Low, 2019, Ng and Ward, 2019, NHMRC NIDRSIGRD, 2021, Woodward and Woodward, 2009).

In addition, multi-component interventions delivered by multidisciplinary teams, such as those delivered to people with dementia, and including COPE, exceed the available [Medicare Benefits Schedule (MBS) funding for allied health](), and the annual subsidy through the Government funded

Home Care Packages. This means that people with dementia in Australia are not able to access a sufficient number of services to meet their health and social needs without occurring additional out of pocket costs (NHMRC NIDRSIGRD, 2021).

Establishing reablement intervention programs with a single point of entry through primary care, that also engages dementia and aged care specialists, would help bring the knowledge and skills required for effective dementia care to primary care. This would also assist with diagnosis, and ongoing support and management of complex cases (NHMRC NIDRSIGRD, 2021).

There is a need to invest in and develop a model of diagnostic and post-diagnostic care that is accessible, cohesive and effective in meeting the needs of people living with dementia (see also Aged Care Royal Commission report, Appendix B recommendations No 15 and No 25). Care models should be co-designed with people with dementia, their care partners, health and aged care, and state and federal governments; and be underpinned by public health, social equity and human rights principles (Attorney-General's Department, n.d, Devandas-Aguilar, 2019). A program evaluation should be embedded from the initiation of such co-design in order to incorporate learnings from the care model implementation at a systems level (NHMRC NIDRSIGRD, 2021).

5 Conclusion and recommendations

Reablement in dementia has the potential to engage a person with dementia in meaningful daily living activities, promote physical and psychosocial function and, consequently, improve their wellbeing.

Evidence-based reablement interventions for people with dementia and their care partners exist but are not routinely implemented in Australia. Work has been done to show how these interventions can advance current dementia care practice and reduce the societal and economic burden of the disease through reduction in healthcare service use, informal care burden and improved quality of life for people living with dementia.

5.1 Dementia must be recognised as a disability and appropriate care should be provided

Dementia is not recognised as a disability. This limits the care that is available for this vulnerable population. The recognition of dementia as a disability and provision of subsequent care by specially trained multi-disciplinary teams will result in more appropriate care, and this should be prioritised.

The NDIS has shown increased focus on the ability of recipients to access social and community activities, as well as informal support networks with care partners. Allowing people with dementia to access funding and support schemes such as the NDIS will enable access to more targeted care for this population.

5.2 Informal care partners must be provided with access to supports at the time of diagnosis

The support for informal care partners needs to extend beyond provision of respite care. Immediately after a person's diagnosis, care partners should be provided with access to preventative care which includes education and training around the disease, symptom management, as well as stress management for self. Allied health professionals with extensive knowledge about non-pharmacological interventions and skills in dementia care should be better utilised in order to improve outcomes for both people with dementia and their care partners.

Collaboration between people with dementia, their care partners, health and aged care, and state and federal governments is essential to the co-design of service models that consider medical and social aspects of dementia for the person and their care partners.

5.3 Allied health care providers should be adequately supported to provide evidence-based interventions

Evidence-based reablement interventions to support people with dementia and their care partners should be offered through government and non-government services through inclusion in Home Care Packages.

Funding to support access to allied health should be prioritised by increasing the limits posed by the Medicare Benefits Scheme for chronic disease management care for people with dementia, or by removing waitlists and providing additional funding that enable access to comprehensive and ongoing multidisciplinary care through the Home Care Package program. Program evaluation of these changes should be conducted which will provide evidence for building and guiding national implementation for change.

5.4 Stigma towards people with dementia among health professionals should be reduced

Targeting misconceptions about dementia and informing health professionals and the general public about available treatments is essential for improving the lives of people with dementia and their care partners and reducing health and social care related costs.

A proactive approach to reducing cultural attitudes and stigma towards dementia should be prioritised by universities, health and aged care organisations. Dementia education should be made mandatory in tertiary education degrees for health professionals (medicine, nursing and allied health) and should be endorsed as an approved area of practice by the Health Practitioner Regulation National Law.

Targeted health education campaigns that engage people with dementia and their care partners in planning and delivery could also be used when addressing evidence-based treatments for dementia. Education campaigns that directly involved people living with dementia as educators have shown to be effective in improving attitudes and reducing the negative stereotypes associated with living with dementia in Australia. This activity should be supported nationally by the Australian Government and at a local level involving community care providers with focus on improving the social aspects of dementia.

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Appendix A. Disability and stages of dementia

Disability is "any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)"(Centers for Disease Control and Prevention, 2020).

Dementia is progressive, and often described in stages: early, moderate, and advanced (Dementia Australia, 2020). The progression through these stages can happen very fast (in a period of just a few months) or more slowly (over several years). The below describes signs and symptoms for each stage of the most common type of dementia, Alzheimer's type Dementia.

Early Stage. The person may show forgetfulness, difficulty in keeping track of the time, or they may become lost in familiar places (World Health Organisation, 2020). The person may show some confusion when completing complex tasks, but can participate in everyday activities such as dressing, bathing, cooking, shopping, and cleaning. It is common for a person to try to cover up mild confusion so family and friends might not notice that something is wrong. The early stage can sometimes be missed as these symptoms are less severe, and they have less impact on the person's functional ability.

Moderate Stage. As the dementia progresses, the signs and symptoms become more obvious. Executive functions such as planning, judgment, and critical thinking are impaired, as is speaking and understanding speech and safety awareness. As a result, the person may find it more difficult to manage work and social life. The person may begin to need help with personal care, they may become more forgetful of people's names or recent events, and they may experience changes in behaviours, such as wandering and repeated questioning (Dementia Australia, 2020).

Advanced Stage. The signs and symptoms become more obvious as the damage spreads through the brain. Sometimes this leads to near total dependency and inactivity (World Health Organisation, 2020). The person may be unaware of time and place, and experience difficulty in recognizing family and friends. They need more help to complete tasks related to personal-care and have trouble with walking. Communication can also be severely impacted, which means that the person has difficulty in expressing their needs. Changes in behaviours may intensify and sometimes include emotional outbursts.

Different types of dementia can progress differently compared with Alzheimer's type described above. Frontotemporal dementia is known to cause changes in behaviour, emotion and personality (Bang et al., 2015, Snowden et al., 2002). Here, the frontal lobes of the brain are impacted first in where memory remains unaffected and the main changes show in personality and behaviour (Snowden et al., 2002). However, if the temporal lobes are impacted first, this is often shown in loss of language skills. The signs and symptoms in dementia of the Lewy body type may vary throughout the day. Here attention and concentration are impacted, and the person may present confused. Hallucinations are common, as are tremors and stiffness that are experienced in Parkinson's disease (McKeith et al., 1996, McKeith et al., 2005). Progression of the Lewy type dementia to later stages is similar to that of Alzheimer's (McKeith et al., 2005, McKeith et al., 1996). Vascular dementia can have a sudden or gradual onset, often caused by stroke or a number of small strokes (Román, 2003). The progression is slow, and the severity increases with each stroke. Memory may be only mildly impacted and this type of dementia is more commonly characterised in early and severe decline in executive function (Looi and Sachdev, 1999).

Overall, the progressive nature of dementia means that a person becomes more dependent on formal or informal supports to assist with care and to remain living at home safely (Australian Institute of Health and Welfare, 2012). Formal support is available through services designated to offer support for older people, including people with dementia, living at home. Informal support is provided by family or friends. Both formal and informal support aims to assist the person with dementia in everyday living activities (such as showering or dressing), household and leisure activities (such as cooking or cleaning), social participation, and to address changes in behaviours attributable to the disease (Australian Institute of Health and Welfare, 2012). The purpose of this support is to improve quality of life for the person with dementia and delay or prevent entry into residential care facilities (Drame et al., 2012).

Appendix B. Recommendations made by the Royal Commission into Aged Care Quality and Safety (2021) endorsed in this brief

Recommendation 3: Key principles

The new Act should:

a. provide that the paramount considerations in the administration of the Act should be:

  i. ensuring the safety, health and wellbeing of people receiving aged care
  ii. putting older people first so that their preferences and needs drive the delivery of care

b. specify the following principles that should also guide the administration of the Act:

  i. older people should have certainty that they will receive timely high quality support and care in accordance with assessed need
  ii. informal carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need
  iii. older people should be supported to exercise choice about their own lives and make decisions to the fullest extent possible, including being able to take risks and be involved in the planning and delivery of their care
  iv. older people should be treated as individuals and be provided with support and care in a way that promotes their dignity and respects them as equal citizens
  v. older people are entitled to pursue (and to be supported in pursuing) physical, social, emotional and intellectual development and to be active and engaged members of the community, regardless of their age or level of physical or cognitive capability
  vi. the relationships that older people have with significant people in their lives should be acknowledged, respected and fostered
  vii. to the fullest extent possible, older people should receive support and care in the location they choose or, where that is not possible, in the setting most appropriate to their circumstances and preferences
  viii. older people are entitled to receive support and care that acknowledges the aged care setting is their home and enables them to live in security, safety and comfort with their privacy respected
  ix. older people should have equal access to support and care irrespective of their location or personal circumstances or preferences
  x. care should be provided in an environment which protects older people from risks to their health
  xi. care and supports should, as far as possible, emphasise restoration and rehabilitation, with the aim of maintaining or improving older people’s physical and cognitive capabilities and supporting their self-determination
  xii. Aboriginal and Torres Strait Islander people are entitled to receive support and care that is culturally safe and recognises the importance of their personal connection to community and Country

xiii. the system should support the availability and accessibility of aged care for all older people, including people of diverse backgrounds and needs and vulnerable people

xiv. the aged care system should be transparent and provide public access to meaningful and readily understandable information about aged care

xv. government entities, providers, health care professionals and aged care workers operating in the aged care system should be open, honest and answerable to older people and the wider community for their decisions and actions

xvi. innovation, continuous improvement and contemporary best practice in aged care are to be promoted

xvii. older people should be supported to give feedback and make complaints free from reprisal or adverse impacts

xviii. people receiving aged care should respect the rights and needs of other people living and working within their environment, and respect the general interests of the community in which they live; the rights and freedoms of people receiving aged care should be only limited by the need to respect the rights of other members of their community

xix. the Australian Government will fund the aged care system at the level necessary to deliver high quality and safe aged care and ensure

Recommendation 15: Establishment of a dementia support pathway

By 1 January 2023, the Australian Government should establish a comprehensive, clear and accessible post-diagnosis support pathway for people living with dementia, their carers and families. This should involve:

a. providing information and advice on dementia and support services, including the aged care system
b. facilitating access to peer support networks
c. providing education courses, counselling and support services
d. providing assistance with planning for continued independent living and access to care, including regular and planned respite for carers.

The Australian Government should provide information and material to general practitioners and geriatricians about the pathway and encourage them to refer people to the pathway at the point of diagnosis.

Recommendation 25: A new aged care program

By 1 July 2024, the System Governor should implement a new aged care program that combines the existing Commonwealth Home Support Programme, Home Care Packages Program, and Residential Aged Care Program, including Respite Care and Short-Term Restorative Care. The new program should retain the benefits of each of the component programs, while delivering comprehensive care for older people with the following core features:

a. a common set of eligibility criteria identifying a need (whether of a social, psychological or physical character) to prevent or delay deterioration in a person's capacity to function independently, or to ameliorate the effects of such deterioration, and to enhance the person's ability to live independently as well as possible, for as long as possible

b. an entitlement to all forms of support and care which the individual is assessed as needing
c. a single assessment process based upon a common assessment framework and arrangements followed by all assessors
d. certainty of funding and availability based upon assessed need
e. genuine choice and flexibility accorded to each individual about how their aged care needs are to be met (including choice of provider and level of engagement in managing care, and appropriate and adapted supports to enable people from diverse backgrounds and experiences to exercise choice)
f. access to one or multiple categories of the aged care program simultaneously, based on need
g. portability of entitlement between providers throughout Australia.

Recommendation 35: Care at home category

The System Governor should be in a position to commence payment of subsidies for service provision within a new care at home category by 1 July 2024. This category should be developed and iteratively refined in consultation with the aged care sector and older people. The starting point for this consultation and refinement process should be that this category:

a. supports older people living at home to preserve and restore capacity for independent and dignified living to the greatest extent and prevents inappropriate admission to long-term residential care
b. offers episodic or ongoing care from low needs (for example, one hour of domestic assistance per week) to high needs (for example, multiple hours of personal care and nursing care)
c. provides a form of entitlement (such as, for example, a budget) based on assessed needs which allows for a coordinated and integrated range of care and supports across the following domains:
    i. care management
    ii. living supports, including cleaning, laundry, preparation of meals, shopping for groceries, gardening and home maintenance
    iii. personal, clinical, enabling and therapeutic care, including nursing care, allied health care and restorative care interventions
    iv. palliative and end-of-life care
d. requires a lead provider to be chosen by the older person. The lead provider will:
    i. be responsible for ensuring that services are delivered to address the assessed needs
    ii. monitor the status of people receiving care and adjust the nature and intensity of the care to meet the person's needs
    iii. seek a reassessment if an increased need persists beyond three months.

Recommendation 36: Care at home to include allied health care

1. From 1 July 2023, the System Governor should ensure care at home includes a level of allied health care appropriate to each person's needs.

2. From 1 July 2024, System Governor should:
   a. ensure that the assessment process for eligibility for care at home identifies any allied health care that an older person needs to restore their physical and mental health to the highest level possible (and maintain it at that level for as long as possible) to maximise their independence and autonomy
   b. ensure that the funding assigned to the older person following the assessment includes an amount to meet any identified need for allied health care, whether episodic or ongoing. This allocation must be spent on allied health care and be consistent with practice guidelines developed by the System Governor
   c. require the older person's lead home care provider to:
      I. be responsible for ensuring that these services are delivered
      II. monitor the status of people receiving care and adjust the nature and intensity of the care provided to meet their needs
      III. seek a new aged care assessment if an increased need persists beyond three months
   d. reimburse the provider for the cost of any additional allied health care needed by the older person through an adjusted Home Care Package, without the need for a new aged care assessment, for a period of up to three months, and undertake a new aged care assessment if the need for additional services persists beyond three months.

Recommendation 42: Support for informal carers

The Australian Government should improve services and support for informal carers by:

a. linking My Aged Care and the Carer Gateway by 1 July 2022, so that informal carers need only use one system to secure respite care and the full range of information, training and support services available on both sites

b. on and from 1 July 2022:

i. enabling direct referral and information sharing for informal carers between My Aged Care, care finders, assessment services and the Carer Gateway

ii. providing accurate and up-to-date information on My Aged Care about the range of supports locally available to informal carers, including training, education, counselling, respite, income support, and, access to the Carers Hub network (once established)

c. on and from 1 July 2023:

i. requiring My Aged Care, care finders and assessment services to identify the primary informal carer when assessing a person for aged care

ii. enabling care finders to refer the primary informal carer to assessment services for assessment for, and access to, formal respite care and other supports available

iii. establishing and funding a community-based Carers Hub network.

Recommendation 80: Dementia and palliative care training for workers

By 1 July 2022, the Australian Government should implement as a condition of approval of aged care providers, that all workers engaged by providers who are involved in direct contact with people seeking or receiving services in the aged care system undertake regular training about dementia care and palliative care.

Recommendation 81: Ongoing professional development of the aged care workforce

From 1 July 2021, the Australian Government and the States and Territories, through the Skills National Cabinet Reform Committee, should fast-track the development by the Australian Industry and Skills Committee of accredited, nationally recognised short courses, skills sets and micro-credentials for the aged care workforce. The courses should be designed to:

a. improve opportunities for learning and professional development, and
b. upgrade the skills, knowledge and capabilities of the existing workforce.

Recommendation 82: Review of health professions' undergraduate curricula

In conducting their regular scheduled reviews of accreditation standards, the relevant accreditation authorities should consider any changes to the knowledge, skills and professional attributes of health professionals so that the care needs of older people are met.

Recommendation 114: Immediate funding for education and training to improve the quality of care

a. The Australian Government should establish a scheme, commencing on 1 July 2021, to improve the quality of the current aged care workforce. The scheme should operate until independent pricing of aged care services by the Pricing Authority commences. The scheme should reimburse providers of home support, home care and residential aged care for the cost of education and training of the direct care workforce employed (either on a part-time or full-time basis, or on a casual basis for employees who have been employed for at least three months) at the time of its commencement or during the period of its operation. Eligible education and training should include:
    a. Certificate III in Individual Support (residential care and home care streams) and Certificate IV in Ageing Support
    b. continuing education and training courses (including components of training courses, such as 'skill sets' and 'micro-credentials') relevant to direct care skills, including, but not limited to, dementia care, palliative care, oral health, mental health, pressure injuries and wound management.
b. Reimbursement should also include the costs of additional staffing hours required to enable an existing employee to attend the training or education. The scheme should be limited to one qualification or course per worker.

Recommendation 118: New funding model for care at home

1. By 1 July 2024, the Australian Government should pay subsidies for service provision within the care at home category through a new funding model that takes the form of an individualised budget or casemix classification. The new funding model should provide an entitlement to care based on assessed need across the following domains: care management

   a. living supports—cleaning, laundry, preparation of meals, shopping for groceries, gardening and home maintenance
   b. personal, clinical, enabling and therapeutic care, including nursing care, allied health care and restorative care interventions
   c. palliative and end-of-life care.

2. The funding model should be developed as part of the development of the new care at home category (see Recommendation 35). Ongoing evidence-based reviews should be conducted thereafter to refine the model iteratively, and ensure that it provides accurate classification and funding to meet assessed needs.

Appendix C. What is occupational therapy

Occupational therapy is an allied health profession that is concerned with participation in everyday tasks taking into consideration a person's cognitive and functional abilities in a specific environment (Occupational Therapy Australia, 2019). Occupational therapists have specialised knowledge and skills which they use to work with people from all backgrounds (ages and abilities). They use these knowledge and skills to assess and identify a person's capabilities and limitations, and analyse the interaction between a person, the environment the person is in, the type of activity the person is engaged in, and the person's ability to perform the activity (American Occupational Therapy Association, 2008). Therapists will then consider strategies that can enhance or maintain a person's functional independence, quality of life and social participation (Steultjens et al., 2004). For people with dementia, occupational therapy has shown to have positive effects in improving independence, functional ability, social participation, and reducing care partner burden (Laver et al., 2017).

Appendix D. Case Study: Care Of People with dementia in their Environments (COPE)

Characteristics of the COPE program

The COPE program aims to increase the person's functional independence and re-engage them in everyday activities while improving their care partner wellbeing (Gitlin et al., 2010).

COPE is multidisciplinary; it combines occupational therapy knowledge and skills together with nursing skills for management of medical symptoms and concerns. The program uses collaborative problem-solving with a therapist and care partner to address the care partner's primary concerns, it incorporates skills building and stress management for the care partner, a step-by-step approach to encouraging the person with dementia to participate in everyday living activities and educating the care partner about how to engage the person with dementia in enjoyable activities based on their cognitive and functional abilities. At the end of the program, the therapist works with the care partner to generalise their learning and plan for future care (Gitlin et al., 2010).

Occupational therapist:

- Visits the person with dementia in their home for up to 10 times over a period of (up to) 4 months.
- Works together with the care partner and person with dementia.
- Assesses what the person living with dementia can do, their previous and current interests, and their physical environment.
- Assesses the care partner, their care concerns, level of stress and readiness to engage with care strategies.
- Assesses the home environment for safety and support of daily activities.
- Educates care partners to problem solve different approaches around modifying their home environment and communication with the person with dementia.
- Provides stress management strategies for the care partner.

- Engages the person with dementia in activities that they can do and have indicated they enjoy doing.

Nurse:

- Supports with medical management.
- Educates around continence, hydration, medication and pain.

Program access and delivery

17 of the approached 24 organisations participated in the program implementation. Participating health professionals and services consisted of government, not-for-profit and for-profit organisations. These were:

Organisations:

- Alwyndor Aged care
- Central Adelaide Local Health Network
- Country Health SA
- ECH Aged care
- Griffith Hospital
- HammondCare
- Hornsby Hospital
- Montefiore Jewish home
- Nepean Blue Mountains Community Services
- SA Older Person's mental Health
- Southern Adelaide Local Health Network
- Uniting Care Wesley Port Adelaide

Private therapists:

- ActiveOT
- Back on Track
- Forest Occupational Therapy
- Mind Plasticity (x2)

Therapists from the participating organisations undertook a 2-day and nurses a half-day training workshop. The workshops were delivered by expert COPE trainers (occupational therapists and a nurse who were taught the program by the original developers, and who had adapted and piloted the training materials to the Australian context). Participating health professionals could also access regular group coaching sessions and join an online community of practice to support mastery of program delivery and implementation (Clemson et al., 2020).

31 (82%) of the 38 trained therapists implemented at least 1 program and of these 18 delivered at least 3 programs which was a requirement for official "COPE trained therapist" certification. Therapists spent almost 2 years in the research project, and it took time to begin deliver the COPE program in their organisation. Of those who implemented programs, only six occupational therapists had not started a program 6 months after attending their respective training. A five-

year prediction of trained and retained therapists was calculated to aid with the economic evaluation of the program (Table 3).

A total of 104 participant dyads in New South Wales and South Australia participated in the study. 25 participant dyads accessed COPE using under the "fee-for-service" model such as the government-funded home care services, Home Care Packages, and private health insurance.

64 participant dyads accessed the program through integration within existing services including community health services, transitional care packages, and aged care service providers. The detail about funding and access pathways in some cases was unclear.

To aid with the economic evaluation of the program implementation in Australia, a five-year prediction of the total number of dyads (person with dementia and their care partner) who will receive the program was calculated as estimated number of therapists trained and average number of participants per therapist a year (Table 3).

Table 3: The estimated number of therapists based on attrition rates, and number of clients receiving the COPE program used in the economic evaluation (Rahja et al., 2020b).

	Year 1 (2020)	**Year 2 (2021)**	**Year 3 (2022)**	**Year 4 (2023)**	**Year 5 (2024)**
Total number of therapists (following attrition for the year)	54	69	78	85	91
Total number of clients receiving the COPE program	270	345	390	425	455

Organisational requirements:

Health professionals needed to commit to and be supported to gain confidence and skills in delivering the program. Some organisational processes also needed to be addressed to help with program uptake and these included (Clemson et al., 2020):

- Need to develop referral pathways and conducted workplace education to inform colleagues about the program (for example, internal presentations).
- One non-government organization spent time planning how they may restructure their services and expand referral strategies to ensure sustainability.
- Private agencies reported that changes in government policies had meant that there was a greater focus on services for younger people with physical disability in comparison to reablement programs for people with dementia and their caseload had changed as a result of this.

Barriers:

Several barriers to the program implementation were also identified and these included (Culph et al., 2021):

- Referrals under the Home Care Packages can be restrictive.
- Scope of occupational therapy practice is commonly confined to only addressing physical issues related to dementia.
- Occupational therapy interventions to date were largely consisted of home modifications, equipment prescription, and falls prevention
- Therapists felt restricted and unable to provide need-specific intervention for people with dementia or their care partners.
- Referrals for occupational therapy were not specifically for cognitive decline or changed behaviours related to dementia and therapists felt they would be going outside their role's scope of practice if they were to explore these issues.

Opportunities

- A free service provided through the government health organisations enabled all people (with dementia) referred to the service to access the program (Culph et al., 2021).
- Management in fee-for service organisations saw (such) innovative program as beneficial to bring in new clients and differentiate their service from competitors.
- There were different opportunities/approaches to fund the program implementation as described by the not-for-profit and for-profit organisations.
- The program enabled therapists to provide more holistic care that was more in-line with the profession's values

Addressing barriers

- Formal training provided as part of the program enabled therapists to address gaps in their knowledge about the program and consequential limited confidence in providing the program (Culph et al., 2021).

Intervention provision

- Therapists from each setting were able to deliver the program and its different components (moderate fidelity).
- The average number of occupational therapy consultation sessions delivered was 7.5 (range 3–10).
- For each program, the occupational therapist spent an average of 13.49 hours face-to-face time plus 6.16 hours of travel time.
- Nurses, who offered one or two consultations, spent an average of 1.97 hours face-to-face time plus 1.77 hours of travel time per program; nurses provided visits in 38% of the completed programs.

Participant and care partner outcomes

- The pre and post evaluation showed a reduction in longer-term, hospital-based, and community-based healthcare service use.
- An increase in services accessed at home (such as personal care or home help).
  Care partners reported spending less time supervising or assisting the person with

dementia in activities of daily living (such as showering, dressing, or eating), and more time assisting the person with dementia in independent activities of daily living (such as shopping, cleaning and community participation).

- Care partners reported a spending less time away from paid employment (Rahja et al., 2020b).
- Post-intervention scores of activity engagement for person with dementia as reported by the care partner were significantly higher than baseline scores (p = .002) with a moderate effect size.
- Only one of the five activity engagement questionnaire items (“In the past 2 weeks, how often has the participant enjoyed doing activities alone”) showed significant improvements from baseline to post-intervention (p = .041)
- Post-intervention scores about care partner well-being and coping (Perceived Change Index) were significantly higher than baseline scores (p < .001) with a large effect size.
- All of the 13 individual items of the Perceived Change Index significantly improved (p < .001) following intervention. Items included, for example, care partner’s ability to understand their loved one’s behaviour, to manage day-to-day caregiving, handle new caregiving problems, feel an improved sense of control over loved one's problems and reduced feelings of being overwhelmed or upset (Clemson et al., 2020).

Ten program participants were interviewed about their experiences and outcomes following their participation in the program (Rahja et al., 2020a):

- Participation was rated (mostly) very valuable.
- Care partners reported the ongoing collaboration between the therapist was empowering.
- Care partners reported feeling that they could continue to provide care at home through learning strategies around stress management and problem solving and receiving support with implementing these strategies.
- Participants described experiences that had enabled the person with dementia to continue to participate in everyday activities. Some described the program had given them a ‘second chance’ to remain living in their own homes and communities.

Economic outcomes

- A detailed cost-benefit analysis showed that the program could reduce societal and economic impact of dementia in Australia (Rahja et al., 2020b). This reduction in impact came from reduction in healthcare service utilisation, informal care burden and improved quality of life for people with dementia.
- By applying shadow prices to appraise the project, the study presented almost A$6.2 million societal gain from the program implementation until 2024 (Rahja et al., 2020b). The gains were most prominent from reduced use of hospital and long-term care services, and reduced community healthcare service use. Other noticeable gains were reduction in time spent caregiving and away from paid employment for care partners, and improvement in the assumed Quality of Life for the participant dyads.
- An inspection of the distribution of the costs and benefits showed that people with dementia and their care partners bear most of the ongoing costs. Reduced fees to access the program would reduce the costs endured by the participants.

- By applying simple economics, the study showed variances in costs and benefits for organisations and therapists delivering the program. For example, if the client fee for accessing the program was reduced, the income for organisations would be less. However, if the therapists spent less time spent delivering COPE (for the same program fee), the organisation's net benefits would increase considerably.

Conclusion

It was possible to implement the COPE program in government-funded health services, non-government organisations, and via private providers.

Therapists' high confidence in the program, intention to deliver and belief that the program was useful to their clients contributed to them implementing and delivering the program.

After receiving the program, people with dementia were more engaged in activities and care partners reported higher levels of wellbeing. The program was considered to improve self-efficacy for care partners and given an opportunity to re-engaged in valued roles for people with dementia.

The final cost-benefit evaluation showed that Australian health and social care system benefits the most out of the program implementation and adoption. A conservative projection (with a total of 1,885 program delivered by 2024) showed approximately A$8.1 million benefit to the health and social care system from the program implementation.

Appendix E. Strengths and limitations of dementia diagnostic settings in Australia

Setting	Role	Strengths	Limitations
Primary care (General practice)	Timely symptom exploration. Initiation of diagnostic investigations. Specialists or memory service referrals for diagnosis confirmation. After diagnosis care provision.	First point of contact for people with dementia and their care partners. Preferred health professional by people with dementia and their care partners.	Limited ability to recognise dementia symptoms: lack of knowledge or confidence. Lack of initiation of cognitive testing: such as limited time to complete standardised assessment tools. Lack of documentation in medical records: fear of stigma, therapeutic nihilism, financial policies
Hospital	Symptom recognition. Initiation of diagnostic investigations. Dementia-specific care provision. Specialists or memory service referrals for diagnosis confirmation. Accurate recording of dementia diagnosis in hospital registries.	Ideal screening opportunity with frequent hospitalisation of people with dementia. Utilisation of in-patient resources, such as brain imaging.	Acute medical issues taking precedence. Lack of time in patient–doctor interaction and poor communication between hospital staff. Concerns regarding stigma, prolonging hospital stay.
Memory clinic	Establish formal dementia diagnosis and aetiology. Prescription of dementia-modulating drugs.	Allows 'one-stop' access to multiple specialist skills. Detect dementia at an earlier stage.	Organisational complexities and overlapping responsibilities.

	Referral to community services. Education and research.	Improve care partner psychosocial well-being.	Problematic cost-effectiveness of memory clinic in practical world.
Specialist	Diagnosis confirmation. Prescription of dementia-modulating drugs.	Increased confidence and ability to diagnose dementia compared with GPs and general internists.	Lack of specialists available and limited opportunities for feedback after consultation. Limited literature evaluating dementia diagnosis by specialists.
Community	Symptom recognition. Specialists or memory service referrals for diagnosis confirmation.	Easy access to specialists (such as geriatricians).	Limited literature evaluating dementia diagnosis in the community.
Residential care	Symptom recognition. Dementia-specific care provision. Specialists or memory service referrals for diagnosis confirmation.	High prevalence of cognitive impairment in care facilities. Potential benefit with collaboration between memory specialist and nursing-home doctor.	Time and labour intensive to have multidisciplinary approach. Limited literature evaluating dementia diagnosis in care facilities.

Adjusted from Ng and Ward (2019)

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