The benefits of physical activity and exercise for people living with dementia

Discussion paper II
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This paper has been developed by the Policy, Research and Information Department, Alzheimer’s Australia NSW. Paper authored by Kylie Miskovski, Senior Research and Policy Officer, Alzheimer’s Australia NSW.

Alzheimer’s Australia respectfully acknowledges the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

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The benefits of physical activity and exercise for people living with dementia

ACRONYMS

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<td>YMCA</td>
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EXECUTIVE SUMMARY

“I feel you’re more alive after exercise!”

(Ron, 93 years old and living with dementia)

There is a growing evidence base for the importance of physical activity and exercise for dementia risk reduction. Less is known however about the benefits of physical activity and exercise for people who have been diagnosed with dementia.

This Alzheimer’s Australia NSW (AlzNSW) discussion paper provides an overview of the benefits of physical activity and exercise for people with dementia and examines the flow on benefits for carers, service providers and Governments. Case studies of good practice are provided to demonstrate to service providers, family carers and people living with dementia how to implement or participate in physical activity and exercise. As government policies and programs emphasise restorative and wellness approaches, it is imperative that service providers understand how to engage people with dementia in physical activity and exercise.

Physical activity is a broad term that includes any body movement that works the muscles and expends energy. It includes incidental movement and activities such as household chores and gardening. Exercise is defined as planned, structured and repetitive physical activity, with the objective of improving or maintaining physical fitness. Engaging in physical activity and exercise can help prevent muscle weakness, mobility problems and other health complications associated with inactivity for people with dementia. It can also help reduce anxiety and depression and increase social inclusion.

In addition to reviewing the existing research on the benefits of physical activity and exercise for people living with dementia, AlzNSW conducted a small qualitative study, interviewing people with dementia and their family carers about their experience. These people identified a number of benefits of participating in regular physical activity and structured exercise programs, across physical, cognitive, social and emotional domains.

People with dementia and carers reported the physical benefits, including feeling stronger, improvements in coordination and balance, and general sense of wellbeing as a result of remaining physically active and exercising. Some also felt that there were cognitive benefits, including a potential correlation between the presentation and progression of dementia and a physically active lifestyle. People with dementia and family members noted that they or the person they support are more alert and communicate more effectively on days they are more physically active.

Many people reported that the benefits of participating in physical activity and exercise are emotional and social, providing opportunities to meet new people and engage with their local community. There is a flow on benefit for people who support people with dementia when people with dementia are participating in physical activity and exercise, including respite opportunities and reductions in carer stress as the unmet needs of people with dementia are addressed.

There are also public policy benefits in spending on physical activity and exercise measures for people with dementia. These include avoiding, reducing or deferring the costs associated with hospitalisations, higher levels of dependence and premature entry to residential aged care.

People with dementia and carers identified barriers to remaining physically active and exercising. These include physical impairments and other disabilities, or declining confidence in their abilities following a diagnosis of dementia. Other barriers are environmental or structural, for example inappropriately designed residential aged care facilities or risk averse cultures.

The ability and capacity of a person with dementia to participate in physical activity and exercise also depends on a number of individual factors including the type of dementia they have, the presenting symptoms, the rate of progression, their personality and whether they were fit and active prior to their diagnosis of dementia.

Barriers to participation and disabling infrastructure and processes need to be overcome. Strategies and programs need to be in place to encourage and enable people with dementia to remain physically active for as long as possible so they can reap the many benefits.

Alzheimer’s Australia NSW makes the following recommendations:

**Policy**

2. The Australian Government fund the development of toolkits for aged care service providers (residential and community) through its Healthy Ageing Grants. The toolkit should be supported by knowledge translation activities which provide guidance to aged care providers on implementing exercise programs for people with dementia and carers.
3. The Australian Government mandate private health insurance rebates for gym memberships and exercise physiologist sessions for people with dementia.
4. The Australian Government provide Practice Incentive Payments to General Practitioners who make referrals to exercise programs for people with dementia following their diagnosis.
5. The Australian Government and the State Governments ensure funding models for health and aged care encourage the delivery of exercise programs for people with dementia by offering funding incentives to aged care providers. This will result in reduced hospital admissions and delay progression to higher levels of dependence.
6. Further research be funded to:
   - understand the amount and type of exercise that is most beneficial for people living with dementia
   - further build evidence base for benefits and how exercise impacts positively on cognition
   - build the evidence base for best practice for delivery and implementation.

**Practice**

7. All private gyms provide education for their staff (for example, exercise physiologists, personal trainers) about dementia to facilitate inclusion of people with dementia into exercise programs and activities.
8. Aged care providers form partnerships with private gyms and personal trainers so as to provide opportunities for their clients with dementia to access these services.
9. Local councils support dementia-friendly community activities through Healthy Active Seniors programs which include people with dementia and draw on volunteer support for group activities such as walking groups, yoga, and tai-chi.
10. Aged care providers put in place programs based on exercise and physical activity examples provided in this report as a way to improve the social and emotional wellbeing of people with dementia. Programs should address the barriers to participation for specific communities.
11. Aged care providers ensure that built environments in residential aged care (especially dementia-specific units) and retirement villages enable mobility and freedom of movement. The models demonstrated in the Dementia Enabling Environments Projects are a good example of this.
12. Providers of exercise programs and services should design their programs to include carers of people with dementia.
13. People with dementia seek out opportunities to participate in exercise or physical activity and seek medical advice before starting. The examples in this paper may give some direction to options to choose from.
PHYSICAL ACTIVITY & EXERCISE FOR DEMENTIA RISK REDUCTION

It is known that physical activity and exercise benefit cognitive functioning, and there are several hypotheses to explain this. For example, the ‘cognitive reserve’ hypothesis proposes that exercise improves blood flow to the brain, leading to a larger cognitive reserve which can be beneficial in neurodegenerative disorders; while the ‘vascular’ hypothesis suggests that aerobic exercise reduces the risk of cardiovascular disease, and the ‘stress’ hypothesis suggests that exercise reduces stress, thereby reducing the risk of dementiai.

There are seven potentially modifiable risk factors for Alzheimer’s disease - diabetes, midlife hypertension, midlife obesity, physical inactivity, depression, smoking, and low educational attainment. Research has found that around a third of Alzheimer’s disease cases worldwide can be related to seven potentially modifiable risk factors. Of the seven risk factors, the authors state that the largest proportion of these cases of Alzheimer’s disease in Western countries could be attributed to physical inactivityii.

Physical activity is one of the important pillars of the Your Brain Matters programiii currently funded by the Australian Government and developed and delivered through the Alzheimer’s Australia federation. Your Brain Matters guides individuals on how to look after their brain health, based on the evidence that modifiable health and lifestyle factors are associated with the risk of developing dementia. Research suggests that living a brain healthy life, particularly during mid-life, may reduce a person’s risk of developing dementia.

There are five steps involved in the program:

- Look after your heart;
- Be physically active;
- Mentally challenge your brain;
- Follow a healthy diet;
- Enjoy social activityiv.

For more information about the Your Brain Matters program, see http://www.yourbrainmatters.org.au/

Although there is a growing body of evidence about physical activity and exercise for dementia risk reduction, less is known about the benefits of exercise for people with dementia.

AIM OF THIS PAPER

This Alzheimer’s Australia NSW (AlzNSW) discussion paper provides an overview of the benefits of physical activity and exercise for people with dementia and the flow on benefits for carers, service providers and Governments.

This paper is timely. As government policies and programs emphasise restorative and wellness approaches, it is imperative that providers of in-hospital and post-hospital, community and residential aged care services understand how to engage people with dementia in physical activity and exercise. Despite this shift in approach and growing evidence of the benefits of exercise and physical activity, people with dementia are still being denied access to or are yet to be fully integrated into programs and services and/or not encouraged to remain physically active.

This paper aims to encourage all stakeholders to take action to enable, support and encourage people with dementia to remain physically active and continue to participate in exercise for as long as possible. Case studies of good practice are provided as examples for service providers, family carers and people with dementia interested in implementing or participating in physical activity and exercise programs or routines. Practice and policy recommendations, developed in consultation with AlzNSW and Anglican Retirement Village (ARV) operational staff, are also provided.
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PROJECT METHODOLOGY

AlzNSW reviewed the existing research literature on the benefits of physical activity and exercise for people living with dementia. Our review found that it is difficult to conduct research in this area for a number of reasons, including:

- the challenges of involving people with dementia in exercise programs, which is then amplified for recruitment and retention in subsequent research studies; and
- the difficulties of attributing causation to improvements in cognition, clinical indicators or behaviour to an exercise regime.

Overall the literature reports the results of clinical trials and observations of service providers but there is very little documented evidence from people with dementia and family carers themselves. It was therefore important for AlzNSW to present the views of people with dementia and carers. In order to do this, we conducted a small qualitative study with a convenience sample of people with dementia and carers recruited through services in NSW. Twenty-two people were interviewed:

- nine low care residential aged care facility (RACF) residents with dementia
- five people with dementia living at home in the community
- eight carers of people with dementia living at home or in residential care.

Case studies of programs and services which demonstrate good practice in enabling people with dementia to remain physically active and participate in exercise were identified through existing networks and a snowball approach. These case studies provide examples for how to engage and support people at varying stages of dementia in physical activity and exercise.

BACKGROUND: THE SOCIAL AND POLICY CONTEXT

DEMENTIA

There are more than 332,000 Australians living with dementia and, without a significant medical breakthrough, that number is expected to increase to almost 900,000 by 2050. Dementia is the single greatest cause of disability in Australians aged 65 years and over, and the third leading cause of disability burden overall. Dementia places significant pressure on care and health budgets, with total direct health and aged care system expenditure on people with dementia at least $4.9 billion in 2009-10.

It is important that people with dementia remain physically active to maintain their physical health and reduce their risk of falls. Exercise and physical activity can also reduce the severity of behavioural and psychological symptoms of dementia (BPSD). These benefits can assist in maintenance of basic activities of daily living (BADLs) and some instrumental activities of daily living (IADLs). Maintaining these activities can slow functional decline and therefore reduce the need for support services early in the progression of the disease. This can enable a person with dementia to remain at home for longer and avoid hospitalisations and premature entry to residential care. Not only is this good for the person with dementia and their family, it also saves individual and government expenditure in terms of hospital and residential aged care costs.

PHYSICAL ACTIVITY AND EXERCISE

Physical activity is a broad term that includes any body movement that works the muscles and expends energy. It includes incidental movement and lifestyle activities such as household chores, gardening and walking. As it is a broad term, physical activity also encompasses structured and planned activities such as sports and exercise. Exercise is more specific and is defined as planned, structured and repetitive physical activity, the objective of which is to improve or maintain physical fitness.

Physical activity is one of the most important steps in increasing and maintaining physical and mental wellbeing and quality of life of older people. It is important for the prevention and management of chronic diseases and has the potential to reduce physical decline, maintain functional ability, reduce the risk of falls, and prevent injuries.

The Australian National Guidelines for Physical Activity recommend at least 30 minutes of physical activity per day for older people, aged 65 years and older. However, only 43% of all adults (aged 18 years and over) actually met the “sufficiently active” threshold in 2011-12. Levels of physical activity tend to decline in older ages; in people aged 75 years and over, the average time spent in physical activity was 20 minutes per day and only one in four in this age group were classified as sufficiently active against the national guidelines.

Key barriers to participating in physical activity for the general population are existing health problems, cultural issues, environmental factors, stress and a lack of time. People with dementia, living both at home and in residential aged care facilities (RACFs), face additional barriers to remaining physically active and participating in exercise, including stigma, negative attitudes about the capability of people with dementia and a culture of risk aversion in aged care.

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1 The project received approval from the Macquarie University Human Research Ethics Committee as per AlzNSW research protocols. Informed consent to be interviewed was obtained from individuals (proxy consent was given by carers in the case of some RACF residents with dementia).

2 BADLs consist of self-care tasks, including: bathing and showering, dressing, eating, functional mobility, personal hygiene and grooming, and toilet hygiene.

3 IADLs are not necessary for fundamental functioning; however they allow an individual to live independently in the community. They include: housework, taking medications as prescribed, managing money, using the telephone and technology, and transportation.
WELLNESS AND REABLEMENT APPROACHES
It has been proposed that the design of the new Commonwealth Home Support Programme be underpinned by a wellness and reablement approach which aims to maximise clients’ independence and autonomy. Wellness is a philosophy that focuses on whole of system support and is based on the premise that even with frailty, chronic illness or disability people generally have the desire and capacity to make gains or maintain their physical, social and emotional wellbeing and to live autonomously and independently. It emphasises prevention, optimising physical function and active participation.

The provision of reablement services is a part of this philosophy. Reablement is the use of timely assessment and targeted interventions to: assist people to maximise their independence, choice and quality of life; appropriately minimise support required and reliance on future and/or alternative support; maximise the cost effectiveness of programmes; and support people to continue to participate and remain engaged in their local communities as they wish. Physical activity and exercise services and programs will be an important component of wellness and reablement approaches.

However, the Productivity Commission in its 2011 review of the Australian aged care system, noted that “there is little incentive for [aged care] providers to invest in activities that promote the restoration of health and functional independence in care recipients as restoration generally results in a reduced care subsidy, particularly in residential aged care”. This is an issue that the aged care sector acknowledges, with the current arrangements providing more funding at the higher levels of the care continuum, which acts in opposition to this objective of promoting health and restorative approaches. Incentivising restoration and improvements in clinical indicators is difficult policy to design, but the Government should pursue this in the future to support Australians to live at home for longer and age well.

THE BENEFITS OF PHYSICAL ACTIVITY AND EXERCISE
The Department of Health outlines the benefits of physical activity for older people:

Being physically active makes you look and feel better.
• Gives you more energy
• Helps you sleep better
• Helps you to relax
• Helps you to meet people and make friends
• Is fun
• Tones your body

Being physically active is good for your mind.
• Reduces stress and anxiety
• Improves concentration
• Improves self-confidence
• Reduces feelings of sadness

Being physically active is good for your body.
• Helps to control:
  - weight (and reduces body fat)
  - blood pressure
  - cholesterol
  - type 2 diabetes
  - bone and joint problems (e.g. arthritis)
• Reduces the risk of:
  - heart disease
  - stroke
  - some cancers
• Helps to manage pain
• Helps to maintain and increase joint movement
• Helps to prevent falls and injury.

Exercise programs for older people often have a falls prevention focus and highlight the benefits of maintaining physical fitness to enable functional independence and continuation of activities of daily living (ADLs). There is limited evidence to guide fall prevention in people with dementia, despite this cohort having a high rate of falls and subsequent fractures and poor outcomes.

Participating in physical activity and exercise can help prevent muscle weakness, mobility problems and other health complications associated with inactivity for people with dementia. It can help promote a normal day-night routine, improve mood and increase social participation. Exercise also plays a part in reducing stress and depression, which are commonly experienced by people with dementia.

4 See, for example, the Australian Government publication A Mature Approach to Staying Active, the Department of Veterans Affairs/Department of Health Choose Health: Be Active – A physical activity guide for older Australians, and the NSW Government’s Active and Healthy program.
THE RISKS OF INACTIVITY FOR PEOPLE WITH DEMENTIA

Low levels of physical activity are a major risk factor for ill health and mortality. People who are not sufficiently physically active have a greater risk of cardiovascular disease, colon and breast cancers, Type 2 diabetes and osteoporosis\textsuperscript{xvii}. People with dementia who are physically inactive face additional risks including:

PAIN

Inactivity is often considered to be part of the apathy symptomatic of dementia, although it could also be a sign of pain. Research has demonstrated a positive relationship between physical inactivity and pain in older people; pain may cause physical inactivity and physical inactivity may cause pain\textsuperscript{xix}.

SLEEP DISTURBANCES

Physical inactivity may contribute to sleep disturbances observed in people with dementia. It may also contribute to the ‘sundowning’ symptoms experienced by some people with dementia. Further research is required to determine the relationship between inactivity and these symptoms.

AGITATION

The use of physical and chemical restraints reduces and minimises the level of physical activity of people with dementia and can aggravate behavioural disturbances such as agitation. The restriction of movement, particularly through the use of physical restraints, produces an increase in stress, damaging those regions of the brain that play a role in cognition and behaviour, and which are already affected in the early stages of dementia. Experts recommend that agitation should not be treated by immobilisation but by an increase in physical activity and exercise\textsuperscript{xx}.

FALLS

People with dementia are at an increased risk of falls, at a rate of at least twice that of older people without dementia\textsuperscript{xxi}. In the general population, the risk of falls is determined by a number of factors, including previous history of falls, balance impairments, muscle strength, coordination and gait, impaired vision, conditions causing low blood pressure, medications, and environmental hazards. For people with dementia, there are additional factors including dementia-specific motor impairments, the type and severity of dementia, and behavioural symptoms of dementia. People with dementia are also more likely to suffer injuries, such as hip fractures, due to a fall than the general older population\textsuperscript{xxii}.

EXISTING RESEARCH

There is much anecdotal evidence on the benefits of physical activity and exercise for people with dementia. However, people with dementia have historically been excluded from research trials of exercise programs due to challenges in recruitment and retention. Fortunately this is changing and there are an increasing number of studies examining the effects of exercise in people with dementia\textsuperscript{xxiii}, although the research evidence base is still limited. An overview of some of these studies is provided below.

The Finnish Alzheimer Disease Exercise (FINALEX) trial is a randomised controlled trial designed to investigate the effects of intense and long-term exercise on the physical functioning and mobility of people with Alzheimer’s disease living at home and the impact on the use and costs of health and social services. The researchers concluded that group exercise sessions and tailored home-based exercises had beneficial effects on the physical functioning of people with Alzheimer’s\textsuperscript{xxiv}.

A recent Australian feasibility study piloted a tailored prevention program to reduce falls in people with mild dementia. The program included home hazard reduction and balance and strength exercises. There was a lower rate of falling and risk of fall in the intervention group; however the researchers recommend that the intervention needs to be tested on a larger sample for the results to be significant\textsuperscript{xxv}.

The Fitness and the Ageing Brain Study (FABS II) is an Australian randomised controlled clinical trial to evaluate the effect of physical activity on cognitive function in people with Alzheimer’s disease. It aims to determine whether physical activity reduces the rate of cognitive and functional decline and improves wellbeing in community-dwelling participants with a diagnosis of mild to moderate Alzheimer’s disease. The study is also examining whether the physical activity intervention eases stress and burden of care\textsuperscript{xxvi}. 
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The Watermemories Swimming Club pilot for people with dementia suggests that a dementia-specific, aquatic exercise program can improve psychological well-being and reduce BPSD in people with dementia living in residential care, and improve staff distress related to BPSD. However because of the multi-faceted nature of the program it is not possible to pinpoint what may have been the most effective component, for example physical activity, socialisation, relaxation etc. The Watermemories Swimming Club pilot for people with dementia implies that a dementia-specific, aquatic exercise program can improve psychological well-being and reduce BPSD in people with dementia living in residential care, and improve staff distress related to BPSD. However because of the multi-faceted nature of the program it is not possible to pinpoint what may have been the most effective component, for example physical activity, socialisation, relaxation etc.

A 2013 scoping study aimed to identify how physical activity may benefit people with dementia; how and/or if current services provide these benefits, and; what support they need to do so. The study found that service providers in the UK are delivering a range of services broadly consistent with the scientific evidence; however there was a lack of alignment between scientific literature and the practice of service delivery. Service providers take a more holistic view of possible benefits, and focus on enjoyment and wellbeing, as well as meaning and purpose for people with dementia, more than the specific cognitive, physical and behavioural outcomes highlighted in the literature. The study concluded that there is a need for more evidence based information and resources to assist in the development of services.

A 2013 Cochrane Review of randomised control trials of exercise programs for people with dementia reported that there is "promising evidence that exercise programs can have a significant impact in improving ability to perform ADLs and possibly in improving cognition in people with dementia". The studies reviewed revealed no significant effect on behaviours of dementia or on mortality, carer burden, and reduction in use of health care services. The Review concluded that further well-designed research is required to examine the outcomes and to determine the best exercise program for people with different types and severity of dementia. The Brain Research Foundation in the USA has funded research to explore the degree to which the amount of exercise slows the progression of Alzheimer’s disease and examine which type of exercise is most effective. It will also investigate the impact of exercise on sleep, and the effect of sleep quality on cognition.

The experience of people with dementia and carers

AlzNSW interviewed people with dementia and carers about the benefits of physical activity and exercise. Twenty-two people were interviewed:

- nine low care RACF residents with dementia
- five people with dementia living at home in the community
- eight carers of people with dementia living at home or in residential care.

Despite the dearth of clinical research evidence, there are many observable benefits of physical activity and exercise for people with dementia. The people with dementia and carers interviewed about their experiences of physical activity and exercise identified a number of important benefits in physical, cognitive, social and emotional domains.

Physical benefits

People with dementia and their carers discussed the physical benefits of being physically active and participating in exercise. They felt stronger, had better coordination and balance, and generally felt a sense of health and wellbeing as a result of physical activity and exercise.

People with dementia living in the community and carers spoke about the routines and regimes they have developed at home and the programs they participate in during the week. For example, Andy, aged 74 and living with a diagnosis of Alzheimer’s disease, walks five kilometres most days and swims three days a week. He has always been ‘fairly active’ and thinks the main benefit of exercise is “staying healthy”. His wife, Robyn, believes that “exercise is a contributing factor to keeping Andy well,” also noting that “it’s something he can do and still do on his own.”

Bill is 77 years old and was diagnosed with Alzheimer’s disease seven years ago. He still lives at home with his wife, Connie. Bill attends a day centre twice a week where he does gentle exercise. He plays competition indoor bowls three times a week at the local club, and attends a seniors’ gym once a week. Bill likes the exercise activities as they give him something to do and he enjoys the time with others. Connie says:

“Everything has improved and he is better than he was before. He is walking for longer and his blood pressure is better.”

Several of the people with dementia interviewed live in low care RACF. Despite their symptoms of dementia, they were able to tell us the types of exercise they participate in, explain why they think it is important to be physically active and articulate the benefits they experience.

Ninety-three year old Ron explained that he does exercises to improve his balance, which has been very important following a fall:

“I think exercise is good, it’s just a bit of a pity that I’ve got this imbalance…I feel [exercise] has stalled it from getting worse, if it’s not improving…I go down to the wall there and do balance exercises and move my feet…I’ve been out there this morning…I feel you’re more alive [after exercise].”

(Ron, 93 years old)

Jean explained the type of exercise she does in the weekly exercise class and what she does independently:

“We have a gentle exercise class once a week, only gentle, nothing too strenuous. We do squats…if I feel like it I use the handrails in the bathroom to do exercise.”

(Jean, 87 years old)

5 Cochrane Reviews are systematic reviews of primary research in human health care and health policy, and are internationally recognised as the highest standard in evidence-based health care. They investigate the effects of interventions for prevention, treatment and rehabilitation.

6 Pseudonyms have been used in reporting the experiences of people with dementia and carers.
And Harriet told us why she exercises and how the staff at the RACF encourage and support her to remain physically active:

“I think it’s good for us. It keeps you going. You’re motivated, you’re keen…I like to walk around a lot…I feel good after the exercise class. I think we need it. I admit I sit a lot more than I did, so I think having it is good. And the lasses are good here [at the RACF], they’ll come and get me and we go for a walk and a sit in the fresh air. And that’s good for us.”

(Harriet, 89 years old)

Residents in RACF also spoke about the importance of remaining physically active, for as long as possible. Jean says:

“I enjoy doing the exercises…they keep you going and keep you moving. I think as long as you’re able to stay upright, that’s the main thing!”

(Jean, 87 years old)

While Jennifer told us:

“It doesn’t matter what age you are, [you can exercise] as long as your heart is okay and you’re not going to pass out!”

(Jennifer, 73 years old)

**COGNITIVE BENEFITS**

Some people with dementia and carers attributed a slow dementia progression to the exercise regimes undertaken. Although there are a number of other factors that need to be taken into consideration, some people did believe that there was a correlation between their gradual progression and presentation of dementia symptoms with a physically active lifestyle. For example, Dave, who was diagnosed with Alzheimer’s disease two years ago when he was in his late 50s, stated:

“I regularly exercise and still engage in sporting activities and socially with other people. In my opinion exercise is a key activity that can delay or lessen the impact that Alzheimer’s can have. I feel confident that the routine exercise I undertake is a contributing factor [to my slow progression].”

(Dave, who has younger onset dementia)

Lucy told us about her sister Hillary’s exercise regime in a RACF. Hillary has always led a physically active lifestyle and, at 91 years of age, she still walks unassisted. She goes for regular walks around the grounds of the facility and does a gentle exercise class every Tuesday. Lucy says:

“I think why Hillary’s done so well and why her dementia has progressed slowly is because of her exercise.”

(Lucy, whose 91 year old sister, Hillary has dementia)

Others noted that they or the person they support were cognitively better on days when they were active. They reported that they were more alert and communicated more effectively after exercising. This was certainly the case for Greta and Mal. Mal was diagnosed with dementia in 2011 and has other health conditions which impact on his mobility and require the use of a walking stick. These physical limitations do not stop him from being physically active though. He still plays lawn bowls, walks around the block most days, and does a tai chi class once a week. His wife, Greta, noted that:

“If Mal doesn’t exercise his balance is very bad and his comprehension is worse, the exercise seems to stimulate him in other ways as well…The exercise is very important because otherwise he just sits and veses on a recliner chair all day.”

(Greta, wife of Mal who has dementia)

While Mal explained the cognitive benefits he feels:

“My mind feels better because the exercise stimulates the mind. And I’m happier in myself because I’ve done something rather than just sit around. Because of my memory the feeling is short-term but I feel better anyway.”

(Mal, late 80s, living with dementia)

Penny told AlzNSW about her mother’s time in a RACF. Her mother had advanced dementia at the time, yet Penny noticed a “real mental improvement” in her mother and the other residents when they had been physically active, noting that “they perked up and it brought them out of themselves”.

Derek is 77 and has early stage dementia. He recently moved to a RACF and has started doing tai chi and gentle exercise classes there. He explained the benefits of these classes:

“I do tai chi. I didn’t really know what it was. I thought it was like judo but then with all the old ladies here I thought ‘no, it can’t be judo’! So I went for the first time…and I really enjoyed it, all the different exercises for all the muscles in your body and it’s a great thing and I like it…I enjoy doing the exercises…they keep you going and keep you moving, I think as long as you’re able to stay upright, that’s the main thing!”

(Derek, 77 years old)

**SOCIAL AND EMOTIONAL BENEFITS**

Several people reported that the benefits of physical activity and exercise were mainly emotional and social. For example, Belinda, whose husband, Gary, was diagnosed with younger onset dementia in his mid-50s, spoke very highly of the dementia-specific gym program he attends. Gary was a professional sportsman and has always been very physically active. Belinda said the benefits of the gym program are “all social” telling AlzNSW:

“It’s his natural environment. He spent his whole life in gyms with sportsmen so he loves going to the gym program.”

(Belinda, wife of Gary who has younger onset dementia)

Participating in an exercise group provides opportunities to meet new people, engage with the local community and be socially stimulated. People with dementia noted improvements in their mood and indicated that being involved in exercise gave them structure and meaning to their day. Mal told us:

“It’s more emotional and social for me, than it is the physical exercise itself. It’s nice to be out in a group and doing things. The motivation to come isn’t really to exercise, it’s to get out and being in the company of people.”

(Mal, late 80s, living with dementia)
BARRIERS AND LIMITATIONS
People with dementia and carers also identified barriers and limitations to participating in exercise and to living a physically active lifestyle. Some had comorbidities and physical impairments unrelated to dementia that limited the type of movement they could do however they were still keen to be active.

For example, 85 year old Margaret has been living with Parkinson’s disease for over forty years and now has early stage dementia. She explained that even though her Parkinson’s symptoms are getting worse, she still tries to keep physically active:

“I exercise to keep my muscles working and stop me from seizing up and feeling pain…Try to keep things working…I can’t stop the shakes…but I think doing the exercises are of great benefit.”

(Margaret, 85 years old with Parkinson’s disease and dementia)

For others, barriers were psychological in nature whereby they had experienced a decline in confidence in their ability following their diagnosis of dementia. Others experienced challenges due to symptoms of dementia, for example, forgetting routines or how to use equipment.

Beverley, who is in her 90s, has recently moved from a low care hostel to a dementia-specific unit (DSU) in a RACF. She was upset that the exercise classes did not appear to be offered in the DSU due to symptoms of dementia, for example, forgetting routines or how to use equipment.

“I would like to be doing some exercise. But there’s no mention of exercise down here, not like upstairs…there was the opportunity for exercise…fairly simple body exercises…all very gentle…I think it does help to keep you in better shape…but there’s not the encouragement down here (in the DSU)”

(Beverley, aged in her 90s)

Many of these limitations and barriers could be overcome with the appropriate support, encouragement and opportunities for people with dementia. People with dementia should not be denied opportunities to be physically active and participate in exercise. Ultimately, fostering a culture of physical activity and the willingness to take risks in a risk averse environment can enable the participation of people with dementia in physical activity and exercise.

For example, ACH Group, a South Australian aged care provider, encourages a culture of exercise and physical activity in its RACFs and community care services. It has a Healthy Ageing Framework in its RACFs, where their Partners in Positive Ageing (PiPA) concept outlines what staff need to know and do to ensure ACH residents age well. In community care, the Encouraging Active Lives in Older People provides information for its support workers about how to support clients to remain physically active.

EXAMPLES OF GOOD PRACTICE
People with dementia should be encouraged and supported to continue with any exercise and physical activity they were doing before their diagnosis. For those who have not been active, the earlier an exercise program can be incorporated into a person’s lifestyle in the early stages of dementia, the more likely it is to be maintained as dementia progresses. In the moderate to late stages of dementia, support and encouragement from family and service providers is important to ensure that people with dementia remain physically active.

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The evaluation of the pilot also found that the social context of a walking group appeared to provide additional benefits of social inclusion and acceptance for people with dementia, their family members and aged care staff. Including people with dementia and the resources developed to support this have now become a standard option for HFW.

7 People in the later stages of dementia should be encouraged to move about regularly where possible. For example, there should be opportunities to sit unsupported and change chairs with supervision.

8 Note: although these services and programs are identified as examples of good practice, this does indicate endorsement by AlzNSW, especially for programs that have not been evaluated.
ALZHEIMER’S AUSTRALIA VICTORIA & YMCA EXERCISE PROGRAM

In 2013, two clients of the Alzheimer’s Australia Victoria Younger Onset Dementia Key Worker Program in Melbourne expressed an interest in accessing an exercise program and improving their fitness. The Younger Onset Dementia Care Consultant liaised with management staff at YMCA Hawthorn to pilot an exercise program specifically designed for people with younger onset dementia.

The pilot was conducted over three months before review. One client resides in a RACF, while the other lives at home. Both clients and their carers were interviewed to ascertain current physical and cognitive capacity, exercise habits and interests, personal fitness and social goals, client and carer identification of limitations or concerns and a social history. This assessment was documented and delivered to the exercise facilitator in a face to face session, along with education resources about dementia, the specific dementia condition of each of the clients and strategies in working with people with dementia. Particular emphasis was placed on working with a person with dementia using effective communication strategies, use of repetition and cues, use of more direct observation and feedback.

YMCA staff designed a suitable exercise program based on individual client interests and specific capabilities and potential limitations. The program is conducted with both clients working together with an exercise facilitator, to enable adequate instruction and supervision and provide socialisation for clients. A comprehensive facility orientation was arranged for the clients, carers and exercise facilitators to explore exercise options and become familiar with the building and surrounds, staff and equipment. Advice for becoming more dementia friendly was also provided to YMCA.

The program is conducted during the middle of the day which is a quiet time in the gym. This allows for clients and their carers to enjoy a social lunch or coffee after the session. The exercise facilitators have found that tone of voice, remaining calm and encouraging and using humour are all important elements of the program. The facilitators report that they focus on what the clients can do, not what they have difficulties with.

Feedback from clients includes: “Our trainer is very good, she doesn’t show frustration, she is patient, and we feel safe and comfortable and respected. It is great to work hard and it suits our age group being at the YMCA in the community. I enjoy the humour and the fun we have. I am sleeping better, I look forward to it, I love the exercise and being with the staff and meeting other people in the gym. I am feeling stronger, have more energy, not as tired. I would go to more sessions if they were available.”

BETTER BALANCE PROGRAM

ARV’s Better Balance program is designed to reduce the risk of falls in older people. It was established in 2008 and now reaches the majority of their independent villages, day respite centres and residential care facilities. Clients and facility residents are assessed by physiotherapists to determine their strength, balance and falls risk and can then join either a group class, a one to one program or be given a home program. An occupational therapy assessment is also offered to all participants. Since the program has commenced ARV have introduced April falls month, Tai Chi and walking groups across the organisation.

Balance training improves strength and fitness, raises awareness and reduces falls, and decreases vulnerability to bone fractures. The Better Balance program is ideal for older people living at home in the community. People with mild to moderate dementia who can follow instructions can benefit from the social and physical aspects of the group programs.

In residential care, the Better Balance program was involved in a pilot with the then Eastern Suburbs Division of General Practitioners in 2012. Twenty people attended 16 group exercise sessions program and ten people participated in individual sessions of Better Balance. The pilot included people with dementia, with scores in the Rowland Universal Dementia Assessment Scale (RUDAS) ranging from 4/30 to 29/30. The ARV residential care staff were instructed in the exercises for people with dementia. Improvements were found in gait speed and physical endurance and there was an increase in quadriceps strength. The satisfaction results showed 91% of program participants enjoyed the classes and 71% felt more confident in walking and balance.

The Rowland Universal Dementia Assessment Scale (RUDAS) is a short cognitive screening instrument designed to minimise the effects of cultural learning and language diversity on the assessment of baseline cognitive performance.

Any score of 22 or less should be considered as possible cognitive impairment and referred on for further investigation by the relevant physician.
**BODY BRAIN FITNESS™ NEURO**

*Body Brain Fitness™ (BBF) neuro is a small group program for people living with a neurological injury or disease. The program has been developed by experienced occupational therapists and physiotherapists from Rehab on the Move, a private neurological rehab team, to help delay the onset of dementia and memory loss.*

Research has demonstrated people with a brain injury are more likely to experience dementia, which often occurs earlier in life than the general population. The BBF™ neuro program has clinically applied the evidence of dementia risk reduction. The BBF™ neuro group members are all limited in their ability to participate in cognitively challenging activities and physical exercise due to their cognitive, physical and behavioural impairments. This limits their ability to access exercise activities, social events and new learning opportunities which may increase their risk of developing dementia.

The BBF™ neuro program is a weekly half-day program with three components:

1. **Physical exercise:** exercises are modified to meet each participant’s physical ability; heart rate is monitored to ensure the group members are achieving the benefits of aerobic exercise, and the facilitator ensures the exercises are a fun experience to ensure the experience is a positive one and long-term benefits are achieved.

2. **Cognitive exercise:** standardised cognitive assessments are used to obtain baseline information at the time of enrolment in the BBF™ neuro group. Cognitive exercises are modified to meet the physical limitations of the group members with a combination of table top activities, computer based activities and group activities.

3. **New learning and participation in enriching activities:** art, drama and public speaking activities are used as opportunities for new learning. Activities are modified physically and cognitively to enable participation for those with physical limitations and to ensure it is cognitively challenging but achievable. This provides an opportunity to build self-esteem and feelings of self-worth.

Each participant requires medical clearance to participate in the exercise program and an initial assessment by an occupational therapist identifies the physical, cognitive and behavioural impairments of each new member in order to make sure they join a group suited to their needs.

This information is used to ensure any necessary adaptations are made to equipment. Any risks associated with the well-being of the participant or other group members and staff are identified and a management plan is developed to ensure everyone’s safety. Each participant identifies what they want to get out of attending the group and goals are established.

Most participants show improved scores on cognition tests, particularly in the areas of memory, attention and problem solving. Feedback from clients and their care workers has identified improvements in behaviour and communication as a result of the program.

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**CENTRE FOR HEALTHY AGEING (CHA)**

*UnitingCare Ageing’s Centres for Health Ageing (CHAs) are seniors gyms located in Lilyfield (CHA West) and Waverley (CHA East). The centres promote the health, fitness and independence of older people and their clientele includes people with a diagnosis of dementia or mild cognitive impairment (MCI).*

CHA members can participate in individual and group based strength training, as well as education sessions about staying healthy and improving wellbeing. Exercise programs are individualised to meet the needs of each member and are regularly evaluated by exercise physiologists on staff.

To be eligible to attend CHA, clients need to be over the age of 60 and live at home. However, in line with the Home Support Programme funding changes clients will soon need to be aged over 65 to be eligible. All clients require a GP referral before commencing. Some CHA clients may be eligible for private health fund rebates.

All new clients start on the CHA introductory package – the Active Ageing Package (AAP). The AAP is a 16 visit starter package which includes an assessment by an exercise physiologist, an individual exercise program, program review (strength testing and goal setting), assisted and non-assisted sessions as well as a final package review. Members are assisted in their first five visits to build confidence in a gym environment.

The exercise programs target the specific needs of members with a variety of chronic diseases and health conditions, including dementia. Results on a range of measures, including functional and strength exercises, demonstrate improvement in members’ functional independence. Functional independence impacts on quality of life and enables older people to remain living in their own homes for longer; therefore, CHAs have been instrumental in enabling older people to continue to live independently at home.

CHA staff develop exercise programs that support clients with dementia to focus on engaging in regular functional strength training. They also assist clients to set up equipment and support them to complete the prescribed exercise independently. While cognitive abilities may vary, thus requiring different levels of support, the key focus areas of enabling wellness, independence and quality of life remain the same.
THE DEMENTIA GYM

The Dementia Gym is coordinated by the Lower Hunter Dementia Advisor. The program aims to provide an opportunity for men living with dementia to attend a local gym with support and access to tailored health and wellbeing programs. The program objectives are to increase fitness levels, improve coordination, core strength, muscle tone, agility, stability, balance and flexibility, socialisation and normalisation.

The program began in October 2013 with funding from Ageing, Disability and Home Care (ADHC) for four men with dementia participating. The men, aged between 62 and 84 years, were reviewed by their GP prior to participating and then gym staff consulted with them and their family carers to establish realistic goals. Individual programs were then developed according to the goals and capabilities of each client.

None of the participants had previously attended a gym; at the initial session they could not identify how to get on an exercise bike or how to pedal it properly. They can now get onto the bike correctly, usually without a cue, pedal the bike for fifteen minutes while throwing bean bags from one of their hands to the other. All participants now box, machine row, use fit balls, hoops, resistant bands, slam balls, leg press and extension machines, flat press, steps ups and dumbbell curls.

There has been measureable improvement in the fitness of each man. The participants and their carers report how important and successful the program has been for their health and wellbeing. The trainers at the gym continue to expand the program to meet the future needs and goals of the program participants, re-assess their physical abilities and ensure it is an enjoyable experience.

YOUNGER ONSET DEMENTIA GYM PROGRAM

Community Gateway (formerly Community Options Illawarra) operates a gym program for clients with younger onset dementia. Their clients identified maintaining physical fitness, muscle strength and good health as a high priority. In response, Community Gateway established an exercise program to cater for their physically active clients with younger onset dementia.

Medical clearance is obtained from GPs prior to commencement for those with chronic health conditions and each client is assessed by personal trainer. Individual programs are developed by the trainer in consultation with clients based on their goals and abilities. Goals may include maintaining physical strength, weight loss and/or social engagement.

The gym fee and personal trainer costs of $60 per session for up to six clients is funded by Community Gateway. Clients pay for their own refreshments at a café following the gym session. Initially, the average cost of a client attending was $32 which included gym and trainer costs, support worker and transport to and from the venue. Now a support worker and transport are provided to the clients by a local respite provider. The clients pay a small contribution towards this service.

In response to a Community Gateway survey, clients reported improved fitness, strength and wellbeing as a result of their involvement in the program. They enjoy the discipline and routine of an exercise program, and the focus and purpose the program provides. They also make new friends and enjoy the outing with the program’s social element (9.8/10) rated as more enjoyable than the exercise component (8.8/10).

PEOPLE WITH DEMENTIA AND CARERS

During the course of the research we also came across a number of carers who have implemented physical activity and exercise regimes with the person they care for. Two such examples are provided below.

Fiona and Jane

Fiona cares for her mother Jane, aged 71, who was diagnosed with dementia two years ago. Fiona works full-time and was concerned that Jane was bored, isolated and unstimulated at home alone for such long periods of time. Following the diagnosis, Fiona initiated an exercise regime for Jane, even though Jane, unlike many of other people interviewed, did not have a history of being physically active throughout her life. Jane said: “I’d never been that much into exercise” while Fiona told us “I’ve never known my mother to be involved in exercise, so this is really good.”

Jane currently goes to the gym three times a week and also has a session with a personal trainer once a week. Jane says “the trainer is pretty spiffy!” At the gym Jane does weights, resistance exercises, boxing, and spends time on the treadmill, bike and rowing machine. Jane walks their dog a couple of times a day and walks up to the shops to get a coffee occasionally. They also use an exercise bike and Pilates machine at home.

Fiona has noticed that her mother is more motivated on her gym days and is now keen to go for bush walks and participate in fun runs on the weekend. Fiona has also noticed improvements in Jane’s symptoms of dementia following exercise:

“...I notice a really positive benefit, I could see straight away that mum was more refreshed and more alive after the exercise...her ability to focus is better, there is some sort of firing going on in the brain, and I think that is not coincidental.”

Robert and Maggie

Robert cares for his mother Maggie who is aged in her mid-80s. Maggie was diagnosed with dementia two years ago. Maggie lives with Robert who works four days a week. Robert says:

“I don’t want mum to sit around and vegetate”

Robert ensures that Maggie is physically active every day. Maggie goes to a specialist seniors’ gym twice a week and a community aged care centre program four times a week. The gym session started as rehab following a hip fracture and the staff continue to support Maggie to participate despite her progressing dementia. The centre-based program involves a combination of art, social and exercise activities.

Maggie enjoys going to these activities. She is very tired after the centre-based program and sleeps very well on the days she attends. She sometimes finds the exercises at the gym challenging because she can’t remember how to do them, however once the exercise has been demonstrated to her a few times she is okay.

Robert also takes Maggie on regular walking outings; for example, she walks to the hairdresser twice a week to get her hair set. Maggie also still does physical chores around the house, such as packing and unpacking the dishwasher, mopping the floor and folding laundry. Robert believes it is important for Maggie to continue to do as much as she can while she is still able to.
DISCUSSION

There are many benefits of staying physically active and exercising for people living with dementia. Much of the evidence for these benefits is anecdotal, hence there is a need for further research including randomised control trials of interventions and evaluation of programs to increase the evidence-base of knowledge and best practice.

The capacity of people with dementia to initiate participation in planned and structured exercise is often questioned. However, our research suggests that some people with dementia, certainly in the early stages of the disease progression, can initiate exercise. Of course, the extent to which this is possible depends very much on the type of dementia an individual has, the presenting symptoms, the rate of progression, their personality and whether they were fit and active prior to their diagnosis of dementia.

Many structured exercise programs for people with dementia are held in indoor venues. Where possible, programs should be held outdoors, to ensure that people with dementia reap the additional benefits of fresh air and vitamin D, which many older people, particularly those living in RACFs, are deficient in. Time outside may also have a subsequent impact on their circadian rhythm which can lead to better quality sleep. If programs are not able to be conducted outside, attempts should be made to ensure participants can see green spaces and sky to simulate the effect of being outside. Such ‘green exercise’ is important for well-being and can benefit people with dementia.

The built environment of some RACFs does not enable people with dementia to access outdoor areas. This has the dual consequences of restricting movement and the benefits of being outdoors. Good design should provide residents with the ability to access outdoor areas that are pleasant and safe, thereby encouraging independent movement and physical activity.

In addition, when people with dementia are physically active and participating in exercise, there are flow-on benefits for family carers and aged care staff. Physical activities and exercises appear to provide a therapeutic benefit in terms of reducing BPSD by meeting needs of people with dementia, which in turn reduces carer stress. Participation in incidental movement or specific exercise programs will assist RACFs in reducing their use of physical and chemical restraint.

Although the primary purpose may be physical activity, our research found that the main benefit of exercise for many people with dementia is the social participation, engagement and community inclusion. These components should therefore be built into exercise routines and programs to ensure that social needs, as well as health and wellbeing goals, are met for people with dementia living in the community and in residential care.

Whilst a person with dementia remains living in their own home with a co-resident carer and participates in exercise, there will be a respite effect for the carer. Alternatively, the carer can join the person with dementia in participating in some programs, thereby also benefiting from health, social and emotional improvements gained through exercise.

People with dementia may represent a market for gyms and personal trainers that could grow with improved access, better knowledge of dementia and information about how to engage people with dementia in exercise programs and activities. The examples in this paper have shown how people with dementia can be supported to exercise in public gyms when a dementia-friendly business welcomes them.

Physical activity and exercise programs for people with dementia also have a public policy benefit. By spending on such preventative and restorative approaches, costs associated with hospitalisations, higher levels of dependence and premature entry to residential care may be avoided, reduced or deferred. Spending on these initiatives also achieves important physical, social and emotional benefits for people with dementia and carers.

Barriers to participation for specific community groups are evident which are exacerbated for people with dementia. These include Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, and people living in rural and remote parts of Australia. Barriers include: cultural inappropriateness, language, dispersed population centres, and isolation. Identifying ways to involve people from different backgrounds in exercise and activity presents an ongoing public health challenge.

Barriers to participation and disabling infrastructure and processes need to be overcome. The benefits of physical activity and exercise are many, and strategies and programs need to be in place to enable people with dementia to exercise and remain physically active for as long as possible.
RECOMMENDATIONS

Alzheimer’s Australia NSW makes the following recommendations:

Policy
2. The Australian Government fund the development of toolkits for aged care service providers (residential and community) through its Healthy Ageing Grants. The toolkit should be supported by knowledge translation activities which provide guidance to aged care providers on implementing exercise programs for people with dementia and carers.
3. The Australian Government mandate private health insurance rebates for gym memberships and exercise physiologist sessions for people with dementia.
4. The Australian Government provide Practice Incentive Payments to General Practitioners who make referrals to exercise programs for people with dementia following their diagnosis.
5. The Australian Government and the State Governments ensure funding models for health and aged care encourage the delivery of exercise programs for people with dementia by offering funding incentives to aged care providers. This will result in reduced hospital admissions and delay progression to higher levels of dependence.
6. Further research be funded to:
   • understand the amount and type of exercise that is most beneficial for people living with dementia
   • further build evidence base for benefits and how exercise impacts positively on cognition
   • build the evidence base for best practice for delivery and implementation.

Practice
7. All private gyms provide education for their staff (for example, exercise physiologists, personal trainers etc.) about dementia to facilitate inclusion of people with dementia into exercise programs and activities.
8. Aged care providers form partnerships with private gyms and personal trainers so as to provide opportunities for their clients with dementia to access these services.
9. Local councils support dementia-friendly community activities through Healthy Active Seniors programs which include people with dementia and draw on volunteer support for group activities such as walking groups, yoga, and tai-chi.
10. Aged care providers put in place programs based on exercise and physical activity examples provided in this report as a way to improve the social and emotional wellbeing of people with dementia. Programs should address the barriers to participation for specific communities.
11. Aged care providers ensure that built environments in residential aged care (especially dementia-specific units) and retirement villages enable mobility and freedom of movement. The models demonstrated in the Dementia Enabling Environments Projects are a good example of this.
12. Providers of exercise programs and services should design their programs to include carers of people with dementia.
13. People with dementia seek out opportunities to participate in exercise or physical activity and seek medical advice before starting. The examples in this paper may give some direction to options to choose from.
The benefits of physical activity and exercise for people living with dementia

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This is an initiative of the Australian Government

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