Engage, Enable, Empower:
Living a healthy lifestyle with dementia or mild cognitive impairment

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Acknowledgements

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Although it might feel like it initially, a diagnosis of dementia is not the end. Speaking from personal experience, life goes on. There are no magic pills to cure dementia, but I’ve found ways to continue living a good life – an active, meaningful life. I’ve accepted that I have dementia but I don’t let that define me. I feel it’s important to maintain my roles as much as possible, as a partner, a friend, and a volunteer. Being actively involved makes me feel better about myself and what I can do. There are some things I can’t do anymore on my own, but I can usually participate in some way with the right support.

In my working life I was a physiotherapist. I loved helping people with their rehabilitation after an injury or illness. It was very difficult when I had to retire earlier than expected. A couple of years ago my partner Graeme and I found a place where I can volunteer using my skills and knowledge as a physiotherapist. I help to run a gentle exercise group for older people with dementia in my local area. I get a lot of satisfaction from helping others in my community to maintain their health.

I am thrilled to have the opportunity to introduce this important publication. I have been involved in the Engage, Enable, Empower project as a consumer advocate over the past two years. It is a health promotion project designed specifically for people living with dementia. Through this project we have developed a range of resources using dementia-friendly principles. This is a huge step in the right direction. As consumers, we want to be informed and involved in our own health care as much as we can.

This numbered publication reviews the evidence that supports the Engage, Enable, Empower resources and key messages for people living with dementia: (1) Keep your mind active; (2) Keep your body active; (3) Get appropriate support; and (4) Look after your health. I have experienced and seen first-hand what a difference it can make to keep active physically, cognitively and socially. I have also found that it’s important to seek out appropriate support and put it in place early, rather than wait until a crisis point. Looking after general health and nutrition can also improve quality of life. This publication is important because we all need to gain a better understanding of what works and what doesn’t for people with dementia. We need to look beyond the medical model and explore what we can do to maintain or improve quality of life.

As a consumer of dementia-related community services, I’d like to advocate for services that do things with us rather than for us. I want to be engaged, enabled and empowered to maintain my valued roles and activities in daily life. I encourage clinicians and service providers to continue reading this paper to learn more about the research and consider how services may be adapted and improved to better meet the needs of people living with dementia. Further research is needed that focuses on ways to improve quality of life. Furthermore, this research needs to be translated to an accessible format for people living with dementia and the people who care about them.

I would also like to take this opportunity to acknowledge the Engage, Enable, Empower project team. Graeme and I really appreciated their dedication and empathy, and feel that this publication is a direct result of their commitment to improving the lives of people living with dementia in the community.

Maxine Thompson
Executive Summary

The prevalence of dementia and mild cognitive impairment (MCI) is increasing in Australia and internationally. Dementia and MCI are conditions characterised by a similar set of symptoms, commonly including cognitive decline and changes in mood and behaviour, with dementia defined by severity of these symptoms sufficient to interfere with daily activities. There are many different disease processes that can lead to these conditions over many years or decades. The progression of symptoms varies from person to person. Pharmacological treatment options are limited, so it is important to consider what non-pharmacological interventions or lifestyle changes may improve outcomes for this growing population. This numbered publication reviews the evidence supporting four main ways to improve health and quality of life when living with dementia or MCI: cognitive interventions, physical activity, accessing appropriate support, and managing health conditions and nutrition.

Research has shown that cognitive interventions can significantly improve outcomes for people with dementia or MCI, including cognitive function and quality of life. The strongest evidence supports the use of cognitive stimulation interventions. In other words, any activity that engages and stimulates the brain is likely to be beneficial. Structured programs such as cognitive training and memory strategy training have also been developed to improve cognitive outcomes, however there is currently insufficient evidence to suggest that these interventions are superior to any other type of cognitive stimulation. Structured cognitive rehabilitation programs have been more effective than standard cognitive training programs, which may be because they are tailored to address the individual’s unique cognitive deficits. Unfortunately, such programs are labour intensive, require a skilled therapist and are not likely to benefit people with moderate to severe dementia. Therefore cognitive stimulation is recommended as the most worthwhile, cost-effective approach to implement for people living with dementia or MCI in all types of settings.

Physical activity has also been shown to improve outcomes for people living with dementia or MCI including improved cognition, physical function and fitness. There is also growing evidence that physical activity may improve quality of life and reduce behavioural and psychological symptoms of dementia. Unless contraindicated, the National Physical Activity Guidelines recommend at least 30 minutes of moderate-intensity physical activity on most days. Any activities that increase cardiovascular fitness, strength, balance and flexibility are likely to be beneficial. Activities should be encouraged that are appropriate to the individual’s physical and cognitive abilities. Apart from these recommendations, there is a lack of evidence to suggest any particular type of exercise program or activity is better than any other. Physical activity has clear benefits for people in all stages of dementia or MCI who are living in residential care or the broader community. Long periods of physical inactivity should also be minimised as it may lead to poorer outcomes including increased pain and changes in behaviour.

People living with dementia or MCI are likely to benefit from a combination of informal social support and health and community services that are responsive to their needs. Social engagement and support often improves quality of life, reduces changes in behaviour, and may even delay cognitive decline. However, research suggests that many people living with dementia or MCI experience a reduction in their social network and underutilise the array of support services that are available throughout Australia. People with dementia commonly need support with activities of daily living such as health care, mobility, transportation and self-care tasks. It is interesting to note that the most commonly reported need by people living with dementia was the need to feel accepted and respected. In addition to traditional medical services, there is growing evidence supporting the value of non-
pharmacological approaches, palliative care services, and technological advances for people with dementia or MCI. A number of complex barriers often prevent people living with dementia or MCI and their carers from accessing appropriate support. It is recommended that services are flexible and responsive to individual needs, ensuring appropriateness for a diverse range of consumers including people from culturally and linguistically diverse (CALD) backgrounds and people with younger onset dementia. Furthermore, information about services should be accessible and designed appropriately for older people who may have limited vision, hearing or ability to acquire knowledge.

Finally, managing health conditions and nutrition effectively can lead to improved health, cognition and quality of life for people living with dementia or MCI. Some health conditions and medications can affect the brain and worsen symptoms, so it is important to consult with a doctor to best manage co-existing conditions such as diabetes or depression. It is also recommended to manage vascular risk factors such as high blood pressure and high cholesterol that can contribute to cognitive decline and illnesses such as stroke and heart disease. Furthermore, it is important that people with dementia or MCI maintain a healthy diet. A Mediterranean-style diet (high in vegetables, fruits, whole grains and healthy fats) with limited processed foods is recommended. Oral nutritional supplements may be useful for some people. Malnutrition can occur amongst people with dementia, so it is important that mealtime issues are identified and addressed as early as possible. Nutrient deficiencies and dehydration can cause cognitive issues. Nutrient supplements may be useful to address specific deficiencies, but there is currently a lack of evidence to suggest that people without nutrient deficiencies will benefit from taking any supplements. Advice should be sought from a doctor or dietician prior to making any changes to diet including nutrition supplements such as vitamins, minerals or other non-prescription remedies.

Few studies have investigated the effects of combining a number of lifestyle interventions into multicomponent programs for people with dementia or MCI, although preliminary research is promising. Further high quality research is strongly recommended to determine what types of interventions or combinations of interventions are most effective for and most important to people living with different stages of dementia or MCI. Future research should focus on outcomes that are of importance to consumers such as quality of life.

Based on the best available evidence, Alzheimer’s Australia has developed health promotion resources entitled Engage, Enable, Empower, which provide accessible information and recommendations for people living with dementia and their carers. The four key messages are: keep your mind active, keep your body active, get appropriate support, and look after your health (managing health conditions and nutrition).

If there are any terms in this publication that you are not familiar with, please see the glossary at the back of the publication.
Introduction

1.1 What is dementia and mild cognitive impairment?

Dementia is an umbrella term for a number of health conditions with similar signs and symptoms that affect everyday function. Dementia may also be called major neurocognitive disorder. The most common forms of dementia are Alzheimer’s disease, vascular dementia, frontotemporal dementia, and dementia with Lewy bodies, however there are many others (AIHW, 2012). Cognitive abilities that may be affected include memory, attention, language, and problem solving. Behavioural and psychological symptoms of dementia are also common, and negatively impact the quality of life of the person with dementia, their carer(s), and family (Beerens, Zwakhalen, Verbeek, Ruwaard, & Hamers, 2013). Behavioural and psychological symptoms of dementia may include depression, anxiety, apathy, agitation, delusions and other psychiatric symptoms.

Dementia is a progressive condition, with biological changes occurring many years before symptoms emerge. Therefore, there is a continuum between what is considered healthy ageing and dementia. Mild cognitive impairment is a diagnosis that may be given to people who experience a slight decline in their memory or other cognitive functions, but no significant loss of function in their daily activities (Levey, Lah, Goldstein, Steenland, & Bliwise, 2006). MCI may also be called mild neurocognitive disorder or prodromal dementia. People with MCI are at higher risk of developing dementia, however some people remain stable and some experience improved cognition over time (Bruscoli & Lovestone, 2004).

1.2 How is dementia treated?

There are currently no known medications to prevent or cure dementia, however there are several medications used to treat cognitive symptoms of dementia, including cholinesterase inhibitors and memantine (AIHW, 2012). Behavioural and psychological symptoms of dementia may also be treated using antidepressant or antipsychotic medications, but some people with dementia may experience significant side effects and/or a lack of improvement in their symptoms (Bains, Birks, & Dening, 2002; Ballard, Waite, & Birks, 2006). Non-pharmacological therapies appear to be a promising approach to improving a range of outcomes for people with dementia and their carers (Gallagher-Thompson et al., 2012; Kverno, Black, Nolan, & Rabins, 2009; Olazarán et al., 2010).

1.3 What is the purpose of this paper?

This paper will focus on the lifestyle factors associated with improved outcomes for people living with dementia or MCI, including improved quality of life, mood, cognition, behaviour, physical health, and ability to participate in activities of daily living. Specifically, this paper will discuss four key strategies for promoting health and wellbeing of people living with dementia or MCI.

The four strategies are

(1) keeping the mind active;
(2) keeping the body active;
(3) accessing appropriate support; and
(4) managing health conditions and nutrition.

These four key strategies are the basis of the Engage, Enable, Empower resources developed by Alzheimer’s Australia.
1.4 What is Engage, Enable, Empower?

‘Engage, Enable, Empower’ are the messages underlying the development of health promotion information and tools specifically for people living with dementia. Several resources have been developed to support the messages. The resources, including a booklet, website and video clips, are designed to be as dementia-friendly as possible. The aim is to enable and empower people living with dementia to remain as engaged as possible with their health care and meaningful activities.

The development of these resources has been guided by this literature review, along with consultation with a broad range of people with dementia, carers and health professionals. Initial work was undertaken by Alzheimer’s Australia Vic, and expanded to become a national project with support from the Australian Government Department of Health.

2 Literature Search Strategy

A literature search was conducted to determine the relationship between lifestyle factors and improved outcomes for people living with dementia. Three research databases (CINAHL, Medline, and Cochrane Library) were searched for peer reviewed journal articles published from 2000 - 2015. In addition, Google searches were conducted for relevant grey literature and websites. The search terms included Alzheimer’s disease, dementia, lifestyle, intervention, rehabilitation, exercise, activity, support, nutrition, and training.

Due to the extensive research in this area and the varied quality of individual studies, this paper will primarily focus on the findings from recent systematic reviews and highlight examples from key studies, reports, or websites.
MIND: Keeping the mind active

Many studies and reviews have suggested that mental stimulation may slow cognitive and functional decline of people with dementia or MCI. Research has been conducted on a broad range of cognitive interventions including cognitive stimulation, cognitive training, cognitive rehabilitation and memory strategies training.

3.1 Cognitive stimulation

Cognitive stimulation refers to all activities that engage and challenge the brain such as studying, cooking or dancing. Cognitive stimulation is generally less formal and structured than other types of cognitive interventions. Often the activities are enjoyable and take place in a social environment (Woods, Aguirre, Spector, & Orrell, 2012). Social activity is mentally stimulating, and therefore can be considered a type of cognitive stimulation. People with dementia often become socially isolated for various reasons such as reduced confidence, apathy or stigma. As a result, people with dementia may experience loneliness, anxiety or depression, as well as cognitive and functional decline. Social interaction may improve mood and engagement in physical, cognitive and self-care tasks such as eating or showering. A recent Cochrane review of cognitive stimulation for people with dementia demonstrated significant improvements in cognition that were retained over time (Woods et al., 2012). There were also improvements in self-reported quality of life and well-being and in staff-reported communication and social interaction. However, there does not appear to be evidence of any significant positive or negative impact on family carers (Aguirre, Hoare, Spector, Woods, & Orrell, 2014; Woods et al., 2012).

It is important to note that dementia can affect an individual’s ability to plan, initiate, and participate in cognitive and social activities. If an activity becomes too demanding or stressful for the person living with dementia or their carer, consider whether it is a meaningful activity for the individual. If so, it is recommended that the issue is discussed with a GP or community support service. Often the activity, the environment or the level of support can be adapted to suit the individual’s current abilities and strengths. People are more likely to engage with activities that they perceive as meaningful and within their abilities. To avoid fatigue and frustration, it is recommended that suitable activities are prioritised to promote engagement of people living with different stages of dementia. For example, an individual with mild dementia or MCI may be able to participate in goal-directed activities such as baking a cake; whereas an individual with moderate or advanced dementia may be able to engage with the activity by watching, helping to stir or decorate, and enjoy the taste and smell of the cake.

3.2 Cognitive training

Cognitive training refers to structured training designed to improve specific cognitive domains, such as memory, executive function, or attention. Cognitive training usually involves repetitive performance of computerised cognitive tasks, although can sometimes be offered in other formats such as pen-and-paper. Three systematic reviews have investigated the effectiveness of cognitive training for people living with MCI and have reported modest benefits. First, a recent systematic review has suggested that cognitive training can improve various aspects of cognitive functioning including memory, executive functioning, processing speed, attention, fluid intelligence and subjective cognitive performance in some people with MCI (Reijnders, van Heugten, & van Boxtel, 2013). A second systematic review by Gates, Sachdev, Fiatarone Singh, and Valenzuela (2011) also found that cognitive training improved memory and global cognitive outcomes, and that it was more effective than memory strategies training. Finally, a Cochrane review of cognitive training for people with MCI suggests that this intervention may
improve immediate and delayed recall compared to no treatment, but does not appear to be significantly better than the alternative treatment control conditions (Martin, Clare, Altgassen, Cameron, & Zehnder, 2011). However, the overall quality of trials investigating cognitive training has been low to moderate (Bahar-Fuchs, Clare, & Woods, 2013; Gates et al., 2011).

Similarly, there is limited evidence of any significant benefits of cognitive training for people living with Alzheimer’s disease and vascular dementia, according to a recent Cochrane review (Bahar-Fuchs, et al., 2013). A study comparing cognitive training to cognitive stimulation (recreational activities) for people with mild to moderate Alzheimer’s disease favoured the cognitive stimulation intervention (E. Farina et al., 2006). Participants who received cognitive training experienced improved function in daily living skills, whereas people who participated in cognitive stimulation experienced improved function, memory, verbal fluency, and fewer behavioural disturbances (E. Farina, et al., 2006). Significant differences between groups were not found at the six month follow up, except that carer distress was lower in the group that received cognitive stimulation.

Another review of three small studies also suggests that people living with mild to moderate dementia can participate in computerised cognitive training to improve their performance in specific functional tasks (Mahendra et al., 2005). Although the improvements were not significant, the participants made fewer errors, took less time and required fewer prompts to complete the target tasks such as learning a new route or shopping for items on a list (Mahendra, et al., 2005).

In summary, there is currently limited evidence supporting the effectiveness of cognitive training for people living with dementia or MCI. It is possible that participants benefited from the intervention in ways that were not adequately captured by the outcome measures used in the studies. Further high quality randomised controlled trials are required to clarify the effectiveness of cognitive training interventions. Overall, cognitive stimulation and cognitive rehabilitation (described below) currently appear to be more promising approaches for people living with mild to moderate dementia or MCI.

### 3.3 Cognitive rehabilitation

Cognitive rehabilitation is a structured intervention that is tailored to individual needs. Preliminary evidence suggests cognitive rehabilitation may have more significant benefits for people with dementia and carers than generic cognitive training interventions (Bahar-Fuchs et al., 2013).

Three randomised controlled trials have shown benefits of cognitive rehabilitation in combination with cholinesterase inhibitors for people with MCI (Rozzini et al., 2007) and people living with early stage dementia (Clare et al., 2010; Loewenstein, Acevedo, Czaja, & Duara, 2004). The benefits for people with MCI included improved memory and abstract reasoning, and reduced behavioural disturbances and depressive symptoms compared to no treatment or cholinesterase inhibitors alone (Rozzini et al., 2007). Loewenstein et al. (2004) found that people with early-stage dementia experienced better task performance on some types of cognitive and functional tasks if they received the systematic cognitive rehabilitation program rather than computer-based mental stimulation activities with a therapist. In the study conducted by Clare et al. (2010), 69 people with Alzheimer’s disease or both Alzheimer’s disease and vascular dementia were randomised to the cognitive rehabilitation group or relaxation therapy or no treatment. The cognitive rehabilitation intervention was individualised to personal goals and provided practical aids and strategies. Techniques for learning, stress management, practice maintaining attention and concentration were also provided. The group receiving cognitive
rehabilitation scored significantly higher on their personal goal performance and satisfaction than the other two groups (Clare et al., 2010).

Although cognitive rehabilitation appears to have benefits for people with dementia or MCI, there are several challenges to implementation for this group (Choi & Twamley, 2013). It is labour intensive, deficit-focused, and may be difficult to adhere to if participants are experiencing memory impairment or lack of motivation. It is likely to be most useful for people with early dementia or MCI, rather than the later stages of dementia.

3.4 Memory management training

The La Trobe University and Caulfield Hospital (LaTCH) memory management training program involves education on memory strategies and use of memory aids. Preliminary evidence suggests that participants are satisfied with the intervention and their achievement of personal memory goals, however benefits have not been observed on neuropsychiatric assessments (Kinsella et al., 2009). Current research is evaluating the implementation of the LaTCH program by service providers and investigating how to make the program accessible to people in rural communities.

Promoting Healthy Ageing with Cognitive Exercise (PACE) was a recent randomised controlled trial of cognitive activity strategy training for people with MCI. Participants were randomly allocated to a 5 week strategy training program or non-specific educational program (Vidovich et al., 2015). The strategy training was focussed on providing participants with strategies and techniques to manage deficiencies in cognition such as memory, attention and word-finding. The education program focussed on providing information about living with dementia rather than skill development. The strategy training group experienced small improvements in attention and quality of life compared to the education group, however overall there were no significant differences in cognition between the groups over a period of two years (Vidovich et al., 2015).

3.5 Multi-component programs

Multicomponent programs also appear to be beneficial for people living with dementia and MCI. A randomised controlled trial found that cognitive rehabilitation combined with social and motor activities and cholinesterase inhibitors may delay cognitive decline and improve mood for people with mild to moderate dementia and MCI (Olazarán et al., 2004). Another randomised controlled trial investigated a 4 week multi-component cognitive rehabilitation program for people with dementia and MCI, that involved activity planning, self-assertiveness training, relaxation techniques, stress management, memory aids, memory training and motor exercise (Kurz, Pohl, Ramsenthaler, & Sorg, 2009). Participants with MCI showed significant improvements in mood, activities of daily living, verbal and nonverbal episodic memory. However, participants with mild dementia did not experience these benefits and only had a small, non-significant improvement in verbal memory (Kurz et al., 2009). These results for people with mild dementia were at odds with the results of recent meta-analyses, so the authors suggested that certain aspects of their program may have been pitched at a level too high for people with mild dementia. It is likely that multicomponent programs may have some benefits for people living with MCI and mild dementia, but may not be appropriate for people with moderate to severe dementia.

3.6 Summary

There is growing evidence that cognitive stimulation and cognitive rehabilitation improves outcomes for people with dementia and MCI. Cognitive stimulation is low cost and simple for formal and informal carers to implement, therefore this approach should be actively supported through policy and education. Cognitive remediation
requires skilled therapists and is a relatively costly intervention to administer. It is likely not a suitable therapy for people with moderate to severe dementia. Further research is recommended to determine who is most likely to benefit from this, and how it can be delivered most effectively. Cognitive training and memory management training also appear to be promising interventions for people with dementia or MCI, although there is currently a lack of high quality evidence to recommend their widespread use.

A review by Kurz, Leucht, and Lautenschlager (2011) suggests the effectiveness of cognitive interventions is similar to current anti-dementia medications. However, strong evidence for delayed cognitive decline, improved engagement in activities of daily living, and achievement of personally relevant goals has only been obtained by single trials. The wide variety of cognitive interventions and outcome measures used in the research have made it difficult for researchers to synthesize the evidence in the reviews discussed above and may obscure the potential benefits of the interventions (Bahar-Fuchs et al., 2013; Reijnders et al., 2013). There is limited evidence regarding which cognitive domains are amenable to change through cognitive interventions (Spector, Orrell, & Hall, 2012) and there is also limited evidence for the generalisability of any improvements in cognition to everyday life activities (Reijnders et al., 2013). Ongoing research will play an important role to clarify the therapeutic benefits and appropriate implementation of cognitive interventions for this population.

4 BODY: Keeping the body active

4.1 Physical activity

There is strong evidence that physical activity has benefits for people across their lifespan, including people at risk of developing dementia (Farrow & Ellis, 2013). There is also growing evidence that people living with dementia can experience a wide range of positive outcomes from participating in physical activity (Miskovski, 2014). A recent Cochrane review of 16 randomised controlled trials found that exercise programs improved the ability to perform activities of daily living and appeared to improve cognition for people with dementia (Forbes, Thiessen, Blake, Forbes, & Forbes, 2013). The included trials varied significantly so there was insufficient evidence to suggest that exercise had a positive impact on other outcomes such as mood, quality of life, and behavioural and psychological symptoms of dementia.

However, Heyn, Abreu, and Ottenbacher (2004) found that exercise training improved fitness, physical function, and behaviour in people with dementia and related cognitive impairment in their meta-analysis of 30 trials involving 2020 participants. Another review of 10 trials investigated motor interventions for elderly people with dementia and found that the intervention improved psychosocial function, physical health, mood, and carer distress (Christofoletti, Oliani, Gobbi, & Stella, 2007). Also, a systematic review by N. Farina, Rusted, and Tabet (2014) found that exercise can slow the rate of cognitive decline in Alzheimer’s disease. Furthermore, a review of 10 studies found that dancing interventions in aged care settings had benefits including reduced changes in behaviour and an increase in social interaction and enjoyment in residents with dementia and staff (Guzmán-García, Hughes, James, & Rochester, 2013).
The majority of trials included in these systematic reviews involved participants in residential aged care facilities. Few adverse effects were noted. The evidence supporting exercise is promising, however the studies were too varied to conclude which type of intervention, frequency, and duration is most effective for people living with dementia. N. Farina et al. (2014) also suggest that it is difficult to draw conclusions when only global measures of cognition are used as the primary outcome or when the measures included in more sensitive cognitive test batteries vary between studies.

Individual studies have shown that aerobic exercise improved cognition in people with dementia (McDonnell, Smith, & Mackintosh, 2011). Multicomponent interventions (a combination of endurance, strength and balance) have resulted in larger improvements in gait speed, functional mobility and balance, compared to progressive resistance training alone (Blankevoort et al., 2010).

A review by Eggermont and Scherder (2006) suggested that exercise programmes should be offered frequently during the week over the long-term, should include a walking activity and take at least 30 minutes in order to improve mood, sleep, and ability to perform activities of daily living.

According to Ahlskog, Geda, Graff-Radford, and Petersen (2011), there are two plausible biological reasons why aerobic exercise may improve cognition. Moderate-intensity exercise may mitigate neurodegenerative processes and age-related loss of synapses, and/or may reduce vascular risk factors that are known to contribute to dementia.

Given the benefits of physical activity, it is not surprising that physical inactivity has been linked to changes in behavioural and psychological symptoms and pain in people living with dementia (Plooij, Scherder, & Eggermont, 2012; Scherder, Bogen, Eggermont, Hamers, & Swaab, 2010). Behavioural and psychological symptoms of dementia and pain may contribute to low levels of physical activity, and physical inactivity may, in turn, contribute to these adverse symptoms. Living in a nursing home is associated with higher rates of physical inactivity, and the use of physical restraints reduces activity to a minimum (Scherder et al., 2010).

While most research has focussed on people with dementia in aged care facilities, recent randomised control trials have investigated the effectiveness of home-based exercise programmes (Cox et al., 2013; Steinberg, Leoutsakos, Podewils, & Lyketsos, 2009; Suttanon et al., 2013). For example, the Fitness for the Ageing Brain Study (FABS) trial assessed the effectiveness of a 6-month physical activity intervention for people with MCI living at home (Lautenschlager et al., 2008). People in the intervention group experienced modest improvements in cognition over an 18 month follow up period. Cox et al. (2010) suggested that interventions that support self-efficacy of participants may improve adherence over the short-term and the long-term. The Fitness for the Ageing Brain Study (FABS) II trial will investigate the effectiveness of the same intervention for people living with dementia and we await the results of this randomised controlled trial (Cyarto et al., 2010). Several other large randomised controlled trials are currently being conducted to assess the value of aerobic exercise (Hoffmann et al., 2013; Hooghiemstra et al., 2012; Pitkala et al., 2010), and balance training exercise for this population (Hill et al., 2009).

4.2 National Physical Activity Guidelines

The evidence described above suggests that physical exercise has many benefits for people with dementia. The National Physical Activity Guidelines for Older Australians offers practical advice for people with dementia or MCI.
4.3 Summary

The research suggests that people living with dementia or MCI benefit from physical activity in a number of ways including improved cognition and physical function. This does not require complex, high cost training programs or highly skilled therapists or carers. It can consist of simple activities such as walking, tai chi, dancing or even housework. There is a lack of evidence to suggest that one type of physical activity is better than another, although people are likely to benefit from participating in a variety of activities that promote cardiovascular health, strength, fitness and balance. Unless contraindicated, people with dementia and MCI should be encouraged and supported to accumulate at least 30 minutes of physical activity on a daily basis. Long periods of passive, sedentary activities should be avoided, or broken up with opportunities to move about. These recommendations are applicable to people living in residential care services as well as people living in the broader community. Even in the more advanced stages of dementia, encouraging physical activity appropriate for the individual is important.

National Physical Activity Guidelines for Older Australians

1. Older people should do some form of physical activity, no matter what their age, weight, health problems or abilities.
2. Older people should be active every day in as many ways as possible, doing a range of physical activities that incorporate fitness, strength, balance and flexibility.
3. Older people should accumulate at least 30 minutes of moderate intensity physical activity on most, preferably all, days.
4. Older people who have stopped physical activity, or who are starting a new physical activity, should start at a level that is easily manageable and gradually build up the recommended amount, type and frequency of activity.
5. Older people who continue to enjoy a lifetime of vigorous physical activity should carry on doing so in a manner suited to their capability into later life, provided recommended safety procedures and guidelines are adhered to.
(Department of Health, 2014)

5 SUPPORT: Accessing appropriate support

Access to appropriate health and community services, as well as informal social support, is clearly important. However, people living with dementia or MCI often experience many barriers to receiving adequate support. Dementia can hinder one’s ability to communicate effectively and seek assistance when required. Therefore people living with dementia in the community and in residential care are likely to have unmet needs. This section of the paper will briefly outline the types of support that may be available to people with dementia or MCI, their support needs, and the barriers and enablers to accessing appropriate support.
5.1 Social support

Social engagement and support are related to improved quality of life and reduced behavioural and psychological symptoms of dementia for people living with dementia (Atoollahi Eshkoor, Hamid, Nudin, & Mun, 2014; Nelson & Tabet, 2015). There is not yet sufficient evidence to confirm whether social engagement slows cognitive decline in people with dementia or MCI, however there are several proposed mechanisms for its benefits (Gow, Corley, Starr, & Deary, 2013). First, social engagement is a type of cognitive stimulation. As discussed earlier in this paper, cognitive stimulation can be an effective intervention for people with dementia or MCI. Research has shown that social stimuli are more engaging than non-social stimuli for people with dementia (Cohen-Mansfield, Thein, Dakheel-Ali, Regier, & Marx, 2010). One-to-one human interaction was most effective in terms of attention, duration and attitude towards the stimulus. Animals, dolls, and animal-like robots also promoted engagement to a greater extent than non-social stimuli such as a ball, puzzle, or folding towels. The second potential reason why social engagement is effective is that it reduces social isolation, in turn reducing depression and the physiological impact of stress (Gow et al., 2013).

There are clear benefits of social interaction, however many people with dementia experience a diminishing network of social relationships and support. Often people living with dementia withdraw from social activities and relationships that they previously enjoyed. Social withdrawal is a common symptom of dementia that can precede cognitive symptoms (Nelson & Tabet, 2015). Withdrawal may also be a conscious choice due to stigma, embarrassment, or a range of other reasons. Friends and family members may also withdraw in some cases (Harris, 2012). People with dementia or MCI, their carers and friends should be educated and supported by service providers to continue their social relationships and interactions as best as they are able.

5.2 Support needs

Dementia is a complex, progressive condition. People living with dementia often require medical, psychological, community and social services. A systematic review noted that the prominent needs include early diagnosis, education, therapy, medication, caregiver support and management of co-existing conditions and changes in behaviour (Weber, Pirraglia, & Kunik, 2011).

The Survey of Disability, Ageing and Carers is a comprehensive national survey that measures the prevalence of disability and long term health conditions amongst older people in Australia, as well as their support needs. The survey found that people with dementia in the community were most likely to need help with the following activities of daily living: health care (84%), mobility (80%), transportation (80%), cognitive and emotional tasks (64%), and self-care (62%) (AIHW, 2012). The survey also found some gender differences, with women more likely than men to need assistance with household chores and cognitive and emotional tasks. Men were more likely to need assistance with home maintenance than women (AIHW, 2012).

A review of 34 studies related to the subjective needs of people living with dementia found that most people reported needs related to well-being and coping, whereas few identified instrumental needs (van der Roest et al., 2007). In this review, the most commonly reported needs were to be accepted and respected, to find adequate coping strategies, and to come to terms with their situation.

People living with dementia and their carers benefit from using community-based services. A review of the evidence found that service users with dementia experienced greater life satisfaction and engagement in activities, and reduced changes in behaviour and communication difficulties. This review also found that carers benefitted, as they experienced less stress, depression, anger, and perceived burden (Ploeg et al., 2009).
Non-pharmacological interventions

There is growing evidence that people living with dementia benefit from non-medical and non-pharmacological approaches to treatment. It has frequently been argued that psychotropic medication has been over-prescribed and over-used in the management of behavioural and psychological symptoms of dementia (Dawson, Bowes, Kelly, Velzke, & Ward, 2015). These medications do not treat the underlying cause of symptoms, may have limited effectiveness in treating symptoms, may have severe side effects and have been linked to an increase in premature deaths. Therefore it is recommended to explore alternative approaches prior to trying psychotropic medications, such as anti-psychotics.

Several systematic reviews have been conducted and have shown the benefits of non-pharmacological interventions such as cognitive interventions and physical activity interventions as discussed in the previous sections of this paper (Ayalon, Gum, Feliciano, & Areán, 2006; Olazarán et al., 2010). The reviews also included a range of other interventions that may be beneficial such as music therapy, reminiscence therapy, aromatherapy, massage, and assistive technology. The research suggests that non-pharmacological approaches may improve quality of life of people with dementia (Cooper et al., 2012) and delay functional decline (McLaren, LaMantia, & Callahan, 2013) and institutionalisation (Spijker et al., 2008). Furthermore, these approaches may reduce symptoms of dementia such as sleep disturbances (Brown et al., 2013), wandering (Forbes, 2007), agitation (Kong, Evans, & Guevara, 2009) and psychological symptoms (Seitz et al., 2012).

Many of these non-pharmacological approaches can be implemented by carers for little to no cost, and few require any specific training (Hulme, Wright, Crocker, Oluboyede, & House, 2010).

Palliative care

Increasingly, dementia is being recognised as a terminal condition and the accessibility of palliative care is improving for this population. However, further improvement is required. Dawson et al. (2015) suggest that provision of palliative care services can be enhanced by developing appropriate assessment, tailored support, and improving coordination of services.

Use of technology

A growing area of research and development is technology designed for people living with dementia and their carers. Simplified videophones, assistance robots, GPS technology and monitoring systems are examples of technological advances that may increase feelings of safety and social connectedness. A systematic review of the research suggests that these types of technology solutions have the potential to alleviate frequently reported unmet needs including the need for information, support to manage symptoms, social contact and health monitoring (Lauriks et al., 2007). They also have potential to reduce carer stress and costs of health care (Buettnner, Yu, & Burgener, 2010), although further research is required to determine which technological advances are effective and in what circumstances.

5.3 Health and community support services

Friends and family carers can offer invaluable emotional and practical support for people living with dementia or MCI. However, the demands of caring can increase over time and it is important that informal care is supplemented by formal support services.

Countries such as Australia offer an array of health and community support services to meet the varied needs of people living with dementia or MCI. General practitioners play an important role in health care, including providing information,
treatment options and referrals to specialists and community support services (Brodaty & Cumming, 2010). As a peak body, Alzheimer’s Australia offers information, education, and support for people living with all types of dementia and MCI and their carers.

The Commonwealth Home Support Programme (CHSP) provides a co-ordinated package of services to enable older people to remain living in their homes. Home care packages can assist with personal care, meals, transportation, domestic tasks, and home maintenance and modification as required. Community nurses also offer assistance to people in their own homes. Many people living with dementia or MCI wish to remain in their home for as long as possible, and also function best in a familiar environment. Services should support clients and their carers to prevent unnecessary transition, and support them through times of transition if required. For short-term support and therapy following a hospital admission, there are transitional care services that are designed to prevent premature entry into residential aged care. If or when residential care is required, an aged care assessment will be carried out to determine whether a low or high level of care is appropriate, or a dementia-specific unit.

The Dementia and Cognition Supplement provides additional funding to home care recipients and aged care services that are caring for people with cognitive impairment associated with dementia and other conditions. This supplement is available in all levels of the Commonwealth funded Home Care Packages Program for people with moderate to severe levels of cognitive impairment associated with dementia or other conditions.

For people with dementia or MCI living in the community, there are often respite options available in-home or at a centre, including day or overnight care (Brodaty & Cumming, 2010). In Australia, day programs are also known as planned activity groups and are usually centre-based, although some involve community outings. There has been limited research regarding the effectiveness of respite services, however they appear to be beneficial to the health and wellbeing of carers. There is no reliable evidence that respite programs have a positive or negative effect on care recipients (Dawson et al., 2015).

My Aged Care was introduced by the Australian Government on 1 July 2013 and consists of the My Aged Care website (www.myagedcare.gov.au) and the My Aged Care contact centre (1800 200 422).

My Aged Care has created a clear entry point to the aged care system and currently provides:

- information about aged care to consumers, family members and carers;
- information for service providers;
- online service finders that provide information about aged care service providers and assessors; and
- online fee estimators for pricing on home care packages and residential care.

### 5.4 Barriers and enablers to appropriate support

A comprehensive range of medical and support services exist for people with dementia or MCI, however research suggests that these services are underutilised (Ploeg et al., 2009). Access Economics reported that more than a third (37%) of Australians living with dementia received no formal support services in 2008 (Brodaty & Cumming, 2010). An American literature review also found that more than half of people with dementia did not receive home and community support services such as personal care, meal preparation, and respite services (Weber et al., 2011). The authors suggest that underutilisation may be due, in part, to a lack of awareness of services. Furthermore, the complexity of the health and social service system may make it difficult for consumers, carers, and health professionals to navigate (Ploeg et al., 2009).
Accessible information is essential for people to better understand what support options are available and what types of interventions are based on reliable evidence. This will assist people with dementia and their carers and health professionals to make timely decisions about accessing services (Dawson et al., 2015). Accessibility of information can be improved by offering it in multiple formats and languages. It is also important to consider that people living with dementia are more likely to experience cognitive, visual and hearing impairments than the general population due to age or symptoms of their condition. For printed and online resources, using a large, sans-serif font, simple language, and contrasting colours is recommended.

In addition to accessible information, help-seeking behaviour promotes access to appropriate services. One study investigating help-seeking behaviour found that older people were likely to have unmet needs for which they have not sought help (Walters, Iliffe, & Orrell, 2001). Barriers to help-seeking may include withdrawal, resignation, and low expectations of the available services (Walters et al., 2001). Furthermore, people with dementia or MCI often experience symptoms which may hinder their ability to seek and navigate the service system.

Considering the timing of help-seeking may also be important for improving outcomes for people with dementia and their carers. A British study found that people from culturally and linguistically diverse backgrounds sought assistance for memory concerns significantly later than Caucasian British people (Dawson et al., 2015). A Canadian community health survey of people with dementia also found that there were gender differences in relation to service use (Forbes et al., 2008). On average, women received more community health services and experienced better health than their male counterparts. Although men received more home care services than women, they experienced poorer health, and therefore their carers were more vulnerable to negative outcomes (Forbes et al., 2008). It is important that services are designed to meet the unique needs of their clients and local communities. Services that are person-centred and culturally appropriate are more likely to promote early help-seeking (Dawson et al., 2015).

Age appropriateness is also an important consideration. People with younger onset dementia such as frontotemporal dementia may experience unique challenges and barriers to accessing appropriate services (Morhardt, 2011). For example, they may not be eligible for services designed for older people or those services may not adequately meet their needs. Furthermore, people with frontotemporal dementia and their families have expressed that they have had difficulty obtaining a diagnosis and have financial concerns due to loss of employment (Morhardt, 2011).

One study investigated why some people with dementia were reluctant to attend day services (Durand, James, Ravishankar, Bamrah, & Purandare, 2009). The most common reasons reported were that they like to be on their own and that they believed they would not enjoy it. They also tended to be concerned about meeting new people, losing their independence and being institutionalised. A screening tool used to detect depression in people with dementia was used, and suggested that more than half of the people who refused day services may meet the criteria for major depression (Durand et al., 2009). This may have contributed to their reluctance to engage with services.

5.5 Summary

People with dementia or MCI are likely to have a broad range of needs for informal and formal support and services. Many require social and emotional support, as well as health and community services. There is growing evidence that non-pharmacological approaches can be therapeutic, cost-effective and simple to implement across all different types of settings. There is also rapid progress in the
development and evaluation of modern technological advances that may improve safety, independence and social connectedness.

It appears that service need and service availability do not adequately predict service use by people living with dementia or MCI and their families. A survey of over 600 carers found that other factors were in fact more predictive of service use, including living arrangement, gender, age, ethnicity, location, availability of transport, health insurance, and the relationship between the carer and person with dementia (Toseland, McCallion, Gerber, & Banks, 2002). Many researchers have noted that services for people living with dementia or MCI are often under-utilised, particularly amongst minority groups. Further research is required to better understand the barriers to accessing appropriate services and addressing these accessibility issues.

6 HEALTH: Managing health conditions and nutrition

6.1 Managing health conditions

Dementia is caused by diseases affecting the brain. If other health conditions that can affect brain function are also present, the symptoms of dementia may be exacerbated. The burden of coexisting medical conditions in Alzheimer’s disease is greater than for individuals without dementia and is associated with poorer cognition (Duthie, Chew, & Soiza, 2011). Therefore management of dementia should include preventative approaches to maintain health and wellbeing as much as possible. The management of other health conditions may have to be modified in the presence of dementia as the person becomes less able to self-manage their healthcare (Hogan et al., 2008).

Delirium is an acute condition with symptoms similar to those of dementia, but usually temporary and reversible. Delirium is common in older people, and even more common in those with dementia where it is associated with accelerated cognitive decline and adverse events. (Nelson & Tabet, 2015). Given the overlapping symptoms, delirium can be difficult to recognise in people with dementia, however, recognition is important as delirium often has an identifiable and treatable cause (Nelson & Tabet, 2015).

6.2 Managing medications

Certain medications, especially those with anticholinergic or sedative effects, can worsen cognition in people with dementia, and adversely affect their physical function and activities of daily living (Bell et al., 2012). They may also blunt the effects of the cholinesterase inhibitors used to treat Alzheimer’s disease (Hogan et al., 2008). Anticholinergics are a class of drugs that block the action of the neurotransmitter acetylcholine in the brain, which is important for memory and cognitive function and is found in reduced levels in Alzheimer’s disease. Drugs with anticholinergic effects include some medications used to treat conditions such as asthma and other respiratory disorders, incontinence, gastrointestinal disorders, muscle spasms, depression and other psychiatric disorders, and sleep disorders. Their use should be minimised in patients with Alzheimer’s disease and other dementias (Bell et al., 2012). In many cases, alternative medications without anticholinergic effects are available. For people with dementia, a medicines review is essential with the aim of reducing or stopping any unnecessary medicines, or
those that are contraindicated or should be used with caution (Pond, 2012). With cessation or reduction of some medications with anticholinergic or sedative effects, the person with dementia may become more alert and engage more effectively (Pond, 2012).

6.3 Vascular risk factors

Modifiable vascular risk factors are common in older people and can contribute to brain vascular disease and cognitive impairment. They include high blood pressure, high cholesterol and obesity, and lifestyle factors such as excessive alcohol consumption and smoking. Price and Keady (2010) suggest that people with dementia can benefit from health promotion initiatives to address these modifiable risk factors. People with vascular dementia are particularly likely to benefit, however vascular risk factors are also strongly associated with Alzheimer’s disease (Duthie et al., 2011) and can be detrimental to people with all types of dementia and MCI. Reduction in blood pressure, cholesterol levels, blood sugar, weight, alcohol intake, and smoking may improve cognitive function or delay the progression of dementia (Pond, 2012).

High blood pressure, or hypertension, is a risk factor for stroke, vascular dementia and Alzheimer’s disease, as well as heart disease and kidney disease, and becomes increasingly common with older age. Treatment of high blood pressure with blood pressure lowering medications has been associated with reduced risk of dementia and better cognitive performance in some studies (Gorelick et al., 2011; Nelson & Tabet, 2015). High blood pressure can lead to damage to brain blood vessels and brain cells and increase the pathology of Alzheimer’s disease (beta amyloid plaques) (Duthie et al., 2011). Low blood pressure (hypotension) in later life can also lead to brain blood vessel and brain cell damage and decreased brain blood flow that can contribute to cognitive impairment (Duthie et al., 2011; Nelson & Tabet, 2015). While the optimal blood pressure for people with dementia has not been determined, careful treatment of hypertension (while avoiding hypotension) is recommended, and is likely to be beneficial in people with dementia or MCI (Nelson & Tabet, 2015).

Diabetes is also associated with an increased risk of dementia (Lu, Lin, & Kho, 2009). Diabetes can lead to blood vessel disease, inflammation and oxidation in the brain, and may also contribute to the pathology of Alzheimer’s disease, all of which increase the risk of dementia. Additionally, several studies have shown that diabetes and poor glucose control are themselves associated with cognitive impairment and greater cognitive decline (Lu et al., 2009; Yaffe et al., 2012). Hyperglycaemia (elevated glucose) adversely affects cognition and is associated with changes in brain blood flow, but this is reversible when good glucose control is restored (Gorelick et al., 2011). Other complications of diabetes such as hypoglycaemia (low glucose), dehydration and infections can also contribute to cognitive impairment (Dunning, Duggan, & Savage, 2014). So careful treatment of diabetes, avoiding hyperglycaemia and hypoglycaemia, is recommended.

High cholesterol in midlife is associated with increased risk of later developing dementia (Anstey, Lipnicki, & Low, 2008). High cholesterol levels increase the build-up of Alzheimer’s disease pathology and contribute to blood vessel damage, increasing the risk of dementia. The use of statins (cholesterol lowering drugs) has been associated with reduced risk of dementia (Swiger, Manalac, Blumenthal, Blaha, & Martin, 2013), although randomised controlled trials of statins for treating dementia per se have failed to show any benefit for cognitive function (McGuinness, 2014). However, for people with high cholesterol and dementia, effective treatment of the high cholesterol has been shown to reduce cognitive decline (Deschaingtre, Richard, Leys, & Pasquier, 2009). There has been some controversy that statins cause memory loss, but recent reviews found no evidence for any adverse cognitive effects of these drugs (Richardson et al., 2013; Swiger et al., 2013).
There has been little research investigating the effects of vascular risk factor treatment in people with dementia. Treating high blood pressure, high cholesterol and diabetes was associated with significantly less cognitive decline in people with Alzheimer’s disease over an average follow up time of 2.3 years (Deschaintre et al., 2009). Neuroimaging studies have demonstrated benefits of vascular risk factor treatment in people with dementia, such as slowed progression of white matter lesions (Richard, Gouw, Scheltens, & van Gool, 2010). In the Deschaintre et al. (2009) study, only 7% of people with Alzheimer’s disease had no vascular risk factors, suggesting these coexisting conditions are common in the dementia population. Given the potential for vascular risk factors to negatively impact the brain and cognitive function, effective treatment is a preventative measure that may help reduce the cognitive burden for people living with dementia or MCI.

6.4 Depression

Depression commonly coexists with dementia and has been found to increase its rate of progression (Nelson & Tabet, 2015). Whether depressive symptoms develop independently from the dementia or are a part of the dementia syndrome is unclear. A history of depression is associated with increased risk of developing dementia, however late-life depression could also be an early sign of dementia (Nelson & Tabet, 2015). Depression is itself associated with cognitive impairment and has serious effects on physical and mental functioning. Depression can interfere with memory and concentration, but these effects can be reversible with treatment. For people with dementia or MCI, depression should be managed with appropriate behavioural and/or pharmacological treatments, with careful monitoring to determine effectiveness and any adverse effects (Bridges-Webb & Wolk, 2003). Effective treatment of depression in people with dementia may have a positive influence on both the depression and the dementia (Nelson & Tabet, 2015).

Biological, psychological and social factors may all play a role in causing depression. Genetic factors, ongoing stress, chronic pain, social isolation, medications, and other illnesses can contribute to depression. Older people (including those with MCI or dementia) may experience depression as a result of major life changes, such as the loss of a partner, retirement, moving into residential care or coping with increasing frailty. However, they are less likely to receive assessment, diagnosis and treatment for depression.

Studies examining the use of antidepressant medications to treat depression in people with dementia have resulted in mixed findings (Bains et al., 2002; NICE, 2006). Some positive effects have been found for slowing cognitive decline, reducing agitation and improving quality of life; however, several large trials conducted in people with dementia have not shown benefit (in group data) for antidepressants for treatment of depression per se (Sepehry, Lee, Hsiung, Beattie, & Jacova, 2012). Continuous antidepressant use has been associated with a reduced rate of cognitive decline in people with depression and Alzheimer’s disease (Mossello et al., 2008). Depression has also been identified as a risk factor for early transition to residential care in people with dementia, with antidepressant treatment seeming to protect against this outcome (Dorenlot, Harboun, Bige, Henrard, & Ankri, 2005). However, a meta-analysis of five randomised controlled trials indicated that antidepressants do not have a statistically significant impact on depression in people with dementia overall (Sepehry et al., 2012). Of course, this does not mean antidepressants will not have benefits for some people with dementia and depression, however non-pharmacological approaches are generally recommended (Nelson & Tabet, 2015). Antidepressant medications with anticholinergic effects (e.g., tricyclic antidepressants) should be avoided because they may adversely affect cognition (NICE, 2006).

Research into non-pharmacological interventions to treat depression in people with dementia has used a number of different approaches or strategies. Interventions that
involved multiple components frequently found significant reductions in depressive symptoms and improved quality of life in the person with dementia (Olaizarán et al., 2010). These findings suggest that an approach that is tailored to the abilities and preferences of the person with dementia and involves multiple intervention approaches may be most beneficial. Multicomponent interventions that were effective typically involved engagement in activities that are enjoyable for the person with dementia plus individualised support (Burgener, Yang, Gilbert, & Marsh-Yant, 2008; Olaizarán et al., 2010).

Research has found that music therapy was associated with reduced symptoms of depression in people with dementia (Cooke, Moyle, Shum, Harrison, & Murfield, 2010; Ueda, Suzukamo, Sato, & Izumi, 2013). A review of music therapy for people with dementia found this to be particularly useful for people with anxiety, and also found that programs of longer duration appeared to be more beneficial (Ueda et al., 2013).

Results of trials examining the effects of support and psychotherapy for people with dementia and depression have been mixed (Olaizarán et al., 2010). A trial involving intensive counselling (30 minutes, three times a week for 16 weeks) reported a significant reduction in depressive symptoms in the intervention group (Tappen & Williams, 2009).

6.5 Nutrition
Nutrition is critically important for health in the general population, including people with dementia or MCI. Dehydration or deficiencies in certain nutrients can cause cognitive problems such as confusion, disorientation or poor memory which can mimic the symptoms of dementia, or make cognitive symptoms worse for someone with dementia or MCI (Yen, 2003).

Several systematic reviews have investigated the potential benefits of specific nutrients for people with dementia. Low levels of omega-3 fatty acid in the brain are associated with cognitive decline, however clinical trials have not demonstrated efficacy of omega-3 fatty acid supplementation in the treatment of dementia (Jicha & Markesbery, 2010). The main dietary source of omega-3 is oily fish, such as salmon, sardines, and fresh tuna (Prince, Albanese, Guerchet, & Prina, 2014). Further research is required to determine whether omega-3 fatty acid supplementation may be useful for people with early stage dementia or MCI (Jicha & Markesbery, 2010).

Similarly, low concentrations of vitamin D have been associated with poor cognitive function, however it remains unclear whether taking vitamin D supplements may have any benefits for people with dementia (Balion et al., 2012; Etgen, Sander, Bickel, Sander, & Förstl, 2012). Low levels of folate and vitamin B12 are also associated with cognitive impairment, yet randomised controlled trials conducted to date have not demonstrated the effectiveness of folate (Malouf & Grimley Evans, 2008) or vitamin B12 supplementation (Ellinson, Thomas, & Patterson, 2004; Malouf & Areosa Sastre, 2003; Vogel, Dalí-Youcef, Kaltenbach, & Andrés, 2009) as a form of treatment. One preliminary study suggested folate may improve the efficacy of cholinesterase inhibitors for people with Alzheimer’s disease, however further research is required (Malouf & Grimley Evans, 2008).

There is also a lack of high quality evidence to suggest that people with dementia or MCI would benefit from taking vitamin B6 (Malouf & Grimley Evans, 2003), thiamine (Rodríguez, Qizilbash, & López-Arrieta, 2001), vitamin E (N. Farina, Isaac, Clark, Rusted, & Tabet, 2012), ginseng (Geng et al., 2010), ginkgo biloba (Birks & Grimley Evans, 2009) or multi-vitamins (Nelson & Tabet, 2015).
Few studies have investigated how complete diets impact on the course of dementia. One study found a correlation between cognitive impairment and a diet high in processed foods amongst people with MCI (Torres et al., 2012). A recent systematic review has shown that adhering to a Mediterranean diet may play a protective role against cognitive decline and development of Alzheimer’s disease (Opie, Ralston, & Walker, 2013). One study found that adherence to the Mediterranean diet was associated with reduced risk of MCI progression to Alzheimer’s disease dementia (Scarmeas et al., 2009). Furthermore, a higher adherence to a Mediterranean diet was associated with a lower risk of mortality for people living with Alzheimer’s disease (Scarmeas, Luchsinger, Mayeux, & Stern, 2007). Consuming this diet rich in fruits, vegetables, low-fat dairy products and minimal saturated fat and sodium may improve outcomes by reducing the vascular risk factors known to contribute to dementia (Yen, 2003).

Medical foods/drinks have been developed specifically to improve brain function of people living with dementia and are sold in Australian pharmacies. Clinical trials have had mixed results, however the findings of one trial suggest that people with mild Alzheimer’s disease may experience modest benefits from the product Souvenaid, including slight improvements in memory and brain electrical activity (Scheltens et al., 2012; Scheltens et al., 2010; Shah et al., 2013). There is a lack of evidence to suggest that medical foods are of benefit to people with moderate to severe dementia.

6.6 Malnutrition

Malnutrition can occur amongst people with dementia (Allen, Methven, & Gosney, 2013). Oral nutritional supplements are products designed to improve nutritional intake and are high in energy, protein, and micronutrients. A systematic review by Allen et al., (2013) found that oral nutritional supplements have positive outcomes for older people with dementia, including weight gain and improved cognition. However, two other reviews suggested there is insufficient evidence to definitively conclude the benefits of thickened fluids and oral liquid nutritional supplements for people with dementia in residential aged care (Hines, McCrow et al., 2010; Hines, Wilson et al., 2010). Hines, Wilson et al. (2010) emphasised the need for nursing and care staff to ensure nutritional supplements are prescribed and administered appropriately.

Some people with dementia experience mealtime difficulties, which may contribute to malnutrition (Aselage & Amella, 2010; Watson & Green, 2006). A systematic review of seven studies suggests that the use of relaxing music during mealtimes may help to reduce agitation or aggression in some older people with dementia, however preferences for music vary from person to person (Johnson, Taylor, Watson, & Huei-chuan, 2011). Extra staff time and staff training has been shown to have a positive effect on nutritional intake of aged care residents with dementia (Cole, 2012). Cole (2012) suggests it is important to identify eating difficulties as early as possible, engage the advice of a dietician, and allow extra time for individuals with dementia to eat.

A larger review of 22 studies (9 randomised controlled trials) found that there were five different types of interventions commonly used to address mealtime difficulties, including nutritional supplements, training/education programs, environment/routine modification, feeding assistance, and mixed interventions (Wen, Jooyoung, & Thomas, 2014). This review concluded that there was moderate evidence supporting the use of nutritional supplements, as well as training/education programs to increase eating time. However, training/education programs and feeding assistance did not significantly improve food intake. Limited evidence supported the use of environmental/routine modification to increase food intake and to reduce agitation (Wen, et al., 2014).
6.7 Frontotemporal dementia and nutrition

People with frontotemporal dementia often experience an increased appetite, increased cravings for sweet foods, and as a result, are likely to gain weight. Some also develop a tendency to eat non-edible things (Ikeda, Brown, Holland, Fukuhara, & Hodges, 2002). It is recommended that people experiencing changes to their appetite or eating, or their carers, should advise their doctor to discuss treatment options. Preliminary research has shown that selective serotonin reuptake inhibitors may be effective in treating behavioural symptoms of frontotemporal dementia including problematic cravings and eating behaviours (Ikeda et al., 2002).

6.8 Eat for Health Australian Dietary Guidelines

The Eat for Health Australian Dietary Guidelines 2013 offer useful suggestions for eating a range of nutritious foods (NHMRC, 2013). An excerpt from these guidelines has been included below. Individuals should consult with their doctor prior to changing their diet or taking nutritional supplements or herbal medicines.

<table>
<thead>
<tr>
<th>Eat for Health Australian Dietary Guidelines 2013</th>
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</thead>
<tbody>
<tr>
<td>1. To achieve and maintain a healthy weight, be physically active and choose amounts of nutritious food and drinks to meet your energy needs</td>
</tr>
<tr>
<td>• Older people should eat nutritious foods and keep physically active to help maintain muscle strength and a healthy weight.</td>
</tr>
</tbody>
</table>

| 2. Enjoy a wide variety of nutritious foods from these five food groups every day: |
| • Plenty of vegetables of different types and colours, and legumes/beans |
| • Fruit |
| • Grain (cereal) foods, mostly wholegrain and/or high cereal fibre varieties, such as breads, cereals, rice, pasta, noodles, polenta, couscous, oats, quinoa and barley |
| • Lean meats and poultry, fish, eggs, tofu, nuts and seeds, and legumes/beans |
| • Milk, yoghurt, cheese and/or their alternatives, mostly reduced fat |
| • And drink plenty of water. |

| 3. Limit intake of foods containing saturated fat, added salt, added sugars and alcohol |
| • Limit intake of foods high in saturated fat such as many biscuits, cakes, pastries, pies, processed meats, commercial burgers, pizza, fried foods, potato chips, crisps and other savoury snacks. |
| • Replace high fat foods which contain predominately saturated fats such as butter, cream, cooking margarine, coconut and palm oil with foods which contain predominately polyunsaturated and monounsaturated fats such as oils, spreads, nut butters/pastes and avocado. |
| • Limit intake of foods and drinks containing added salt. |
| • Read labels to choose lower sodium options among similar foods. |
| • Do not add salt to foods in cooking or at the table. |
| • Limit intake of foods and drinks containing added sugars such as confectionary, sugar-sweetened soft drinks and cordials, fruit drinks, vitamin waters, energy and sports drinks. |
| • If you choose to drink alcohol, limit intake. |

4. Care for your food; prepare and store it safely (NHMRC, 2013).
6.9 Summary

Managing health conditions and nutrition when living with dementia or MCI can be challenging, but the research suggests that this can promote cognitive function, quality of life and related outcomes. Some health conditions can exacerbate the symptoms of dementia, and therefore should be well-managed or prevented where possible. Addressing vascular risk factors such as high blood pressure and high cholesterol is likely to improve cognition and reduce the risk of stroke, heart disease, diabetes and a range of other conditions. Other co-existing conditions such as diabetes, depression and delirium should be well managed, and medications should be reviewed regularly to avoid continued use of medication that is unnecessary or contraindicated for people with dementia.

Nutrition can play an important role in managing the health and wellbeing of people living with dementia or MCI. People who are dehydrated or malnourished are likely to experience cognitive problems. While some nutrient deficiencies are related to poor cognition, there is a lack of high quality evidence to suggest that particular vitamin or nutrient supplements are effective as a treatment option for people with dementia or MCI. There has also been limited research regarding which types of complete diets may be beneficial, but there is some evidence that adherence to a Mediterranean diet may reduce cognitive decline and risk of mortality. Also, a diet high in processed food may be related to cognitive impairment. For general guidance regarding a healthy diet, the Eat for Health Australian Guidelines may be useful. Malnutrition and weight loss are common and can be a serious issue for people with dementia. The research suggests that it’s important to identify mealtime issues early and consult with a dietician. In a residential care setting, additional staff time and training and environmental/routine modification may improve outcomes. People with frontotemporal dementia may experience appetite changes and weight gain. It is recommended that individuals discuss their nutritional needs with their doctor, and seek medical advice prior to changing their diet, nutritional supplements or non-prescription medicines/herbal remedies.

7 Conclusion

Lifestyle factors can have a significant impact on the cognitive and physical function, quality of life and health of people living with dementia and MCI. While medical treatment options are currently limited, non-pharmacological interventions have emerged as a useful, versatile and cost-effective option to improve a broad range of outcomes for people across the course of Alzheimer’s disease and other types of dementia and MCI. In particular, cognitive interventions, physical activity, appropriate support and management of health and nutrition have the strongest evidence to support and recommend their use. At present, the quantity and quality of research in this area is limited, but is certainly promising. Even small delays in the onset or progression of symptoms could greatly improve quality of life and reduce the burden of disease (Deweerdt, 2011).
Glossary

Adherence
Adherence is the extent to which an individual follows a treatment plan (e.g. medication, exercise regime, diet, etc.) without close supervision.

Aerobic exercise
Aerobic or endurance exercise is physical activity that increases your breathing rate and heart rate. Performed regularly it improves physical endurance and the health and fitness of your lungs, heart, and blood vessels. It includes moderate-to-high intensity activities like walking, jogging, swimming, cycling and even energetic housework.

Alzheimer’s disease
Alzheimer’s disease is a physical brain disease that causes dementia. It is named after Alois Alzheimer, who first described it in 1907. The brain degeneration that occurs in Alzheimer’s disease affects memory, thinking skills, emotions, behavior and mood. As a result, a person’s ability to carry out daily activities becomes impaired. As the disease progresses, symptoms worsen. Alzheimer’s disease is characterized by an abnormal build-up of a protein called beta amyloid, which forms ‘plaques’ outside brain cells. Inside brain cells, another protein called tau builds up into ‘tangles’.

Apathy
Apathy may be defined as a lack of interest, motivation or concern for things that others generally find interesting. Apathy is a common symptom of dementia and MCI.

Behavioural and psychological symptoms of dementia
The term “behavioural and psychological symptoms of dementia” encompasses an array of non-cognitive symptoms that are often associated with dementia. Symptoms may include changes in behaviour, mood or perception, such as wandering, agitation, sexual dis-inhibition, depression, anxiety, or delusions.

Cholinesterase inhibitors
Cholinesterase inhibitors are medications that inhibit a brain enzyme and increase levels of a chemical (acetylcholine) that is deficient in some dementias.

Cognitive decline
Cognitive decline is a gradual decrease in cognitive function over time. Cognitive decline is a defining feature of MCI and dementia.

Cognitive function
Cognitive function is the process by which we perceive, think, and understand information and ideas.

Cognitive rehabilitation
Cognitive rehabilitation is an individualised intervention designed to relearn and improve areas of cognition affected by dementia or other brain conditions or injuries. It is delivered by a trained therapist and involves structured skills training and practice to compensate for cognitive deficits. This intervention may be suitable for people with mild dementia or MCI.

Cognitive stimulation
Cognitive stimulation is the provision of individualised or group activities that engage and stimulate. This intervention aims to improve cognition, mood and functioning for people living with dementia or MCI.

Cognitive training
Cognitive training is structured practice to improve specific aspects of cognitive functioning such as memory, attention and processing speed. This practice is often completed individually using a computer program, but may also be delivered in groups and/or using paper-based worksheets. This intervention is designed for people with mild dementia or MCI.
Cognition
Cognition is the collection of mental abilities related to perceiving, thinking and understanding. This includes memory, learning, attention, language, decision making, reasoning, judgment, comprehension, spatial skills and planning.

Dementia with Lewy bodies
Dementia with Lewy bodies is a type of dementia characterised by cognitive decline. Often people with this condition also experience hallucinations. It is closely related to Parkinson’s disease and has been attributed to the presence of abnormal clumps of proteins in the brain known as Lewy bodies.

Depression
Depression is a mental illness that is defined by a persistent low mood that interferes with daily life. People with depression often experience changes to their thinking, behavior and feelings, and withdraw from activities that they previously enjoyed. Often people also experience changes to their memory, concentration, sleep and appetite.

Diabetes
Diabetes is a chronic condition in which the pancreas does not produce enough of the hormone insulin or the body does not respond appropriately to it. This results in abnormally high levels of glucose (sugar) in the blood, which must be monitored and managed to avoid complications.

Episodic memory
Episodic memory is a category of long-term memory that involves the recollection of specific events, situations and experiences, such as your first day of school or attending a friend’s birthday party. In addition to the event itself, episodic memory also involves your memory of the place and time that the event occurred, as well as the emotions, sights, sounds and smells associated with the event.

Executive function
Executive function is an umbrella term for high-level cognitive abilities that influence more basic abilities like attention, memory and motor skills. Executive functions include organisation, planning, sequencing, problem solving, cognitive flexibility, abstract thinking, self-control, emotional regulation, monitoring internal and external stimuli, initiating and inhibiting behaviour, reasoning and decision-making.

Exercise
Exercise is a type of physical activity that is planned, often with the objective of improving or maintaining aspects of physical fitness.

Frontotemporal dementia
Frontotemporal dementia is a form of dementia that involves damage to the frontal and/or temporal lobes of the brain. Behaviour, language and other cognitive skills are affected.

Mediterranean diet
A diet which places particular emphasis on fruits, vegetables, fish and healthy fats.

Meta-analysis
A meta-analysis takes the data from all similar studies and combines them, providing an overall result from all the relevant research. This is a higher level of evidence that is more convincing than a finding from any single study.

Mild cognitive impairment
Mild cognitive impairment (MCI) is defined by a decline in cognitive functions such as memory and thinking skills. It is an intermediate stage where decline is greater than what is experienced through normal ageing, but less severe than dementia. People with MCI have an increased risk of dementia, however a diagnosis of MCI does not necessarily progress to dementia.
Non-pharmacological interventions
Non-pharmacological interventions are treatments or approaches that may be pursued as an alternative to medicine. People with dementia or MCI may benefit from non-pharmacological treatment such as cognitive interventions, physical activity, music therapy, or a range of other activities or interventions.

Palliative care
Palliative care is an approach to service delivery that focuses on improving quality of life and reducing suffering of people with life-threatening illness such as advanced dementia.

Randomised controlled trials
Randomised controlled trials are a type of scientific experiment. They involve randomly allocating individuals to a treatment (e.g. drug or behavioural intervention) or a no-treatment (placebo) condition. A well-managed randomised controlled trial provides a higher quality of evidence than other types of experiments.

Saturated fats
Saturated fats are those that tend to be solid at room temperature and can be found in whole milk, cream, butter, cheese, meats, coconut oil, palm oil, chicken skin, biscuits and pastries. Many ‘fast food’ products, processed meats and deep fried food also contain saturated fats. Saturated fats contribute to the risk of heart and brain disease by raising blood cholesterol levels.

Selective serotonin reuptake inhibitors
Selective serotonin reuptake inhibitors are medications that increase the amount of a neurotransmitter called serotonin between cells in the brain. They are commonly used to treat psychological symptoms related to depression and anxiety.

Self-efficacy
Self-efficacy is an individual’s estimate or personal judgment of their own ability to succeed in reaching a specific goal, for example, quitting smoking or losing weight.

Systematic review
A systematic review is a structured review of the literature that identifies, appraises, and synthesises relevant high quality research to address a specific research question.

Vascular
Vascular means ‘related to blood vessels’. Vascular risk factors are those that can affect the health and function of our blood vessels, including high blood pressure and high cholesterol.

Vascular dementia
Vascular dementia is a form of dementia associated with problems of circulation of blood to the brain. It can sometimes result from a stroke or many mini-strokes.
References


Engage, Enable, Empower
livingwellwithdementia.org.au

FIGHTDEMENTIA.ORG.AU

Visit the Alzheimer’s Australia website for comprehensive information about dementia, care information, education, training and other services offered by member organisations.

or for information and advice contact the

NATIONAL DEMENTIA HELPLINE
1800 100 500
Helpline is funded by the Australian Government

or the Dementia Behaviour Management Advisory Service (DBMAS)
1800 699 799