

Supporting independence and function in people living with dementia

An information booklet of
reablement programs for
people impacted by dementia.

Second Edition



COGNITIVE
DECLINE
PARTNERSHIP
CENTRE

HammondCare
Champion Life



Information to help people living with dementia, and their supporters, to make better informed choices about programs that could maintain or improve function and quality of life.

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Foreword

My name is Theresa Flavin and I've been living with dementia for the past 7 years. Receiving a diagnosis of dementia or even suspecting that you may be starting to feel the symptoms can be devastating. It can be

difficult to feel positive about the future especially when you are told that there is no cure. However, even though there is no way to change what's happening in your brain, you can definitely change how well you use the parts that are still working. Reablement for me, showed me that while the disease was affecting my brain, there was still plenty of unaffected brain tissue that I could use. It's like when you break your leg and it's in a cast, you lose muscle, but strength can often be regained if you do the right exercises. I think that the brain and the body work together in harmony, and reablement can help build new brain pathways and help you stay well for longer. I had the privilege of being invited to review this booklet, and it makes me hopeful for the future to see how far we have come in developing supports to help us to continue living well with dementia.

I'm delighted to see that scientists, doctors and researchers all over the world are starting to show that reablement is possible, and that these therapies could help delay the inevitable decline that dementia brings. Don't give up hope! Stay engaged with the world and discover the new therapies that are being developed to help us live as well as possible with dementia.

Theresa

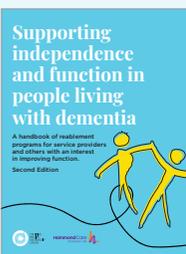
Person living with dementia and HammondCare Dementia Centre
Lived Experience Associate Consultant

Who is this information for?

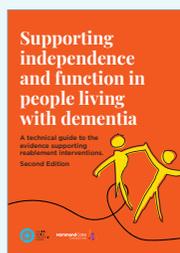
This *booklet* is primarily for people living with early to moderate dementia, along with family members and others who provide support, however, some programs and interventions may also be applicable later in the course of dementia.

In this *booklet* we provide information that we hope will help people living with dementia, and those providing them support, to make better and more informed choices about reablement programs that could maintain or improve function and quality of life.

The *booklet* is one of three that aim to bring together the best research evidence on methods that have been shown to help maintain, delay decline, or improve function for people living with dementia. This project has built upon the recommendations of the *Australian Clinical Practice Guidelines and Principles of Care for People with Dementia*, which can be found at <http://sydney.edu.au/medicine/cdpc/resources/dementia-guidelines.php>



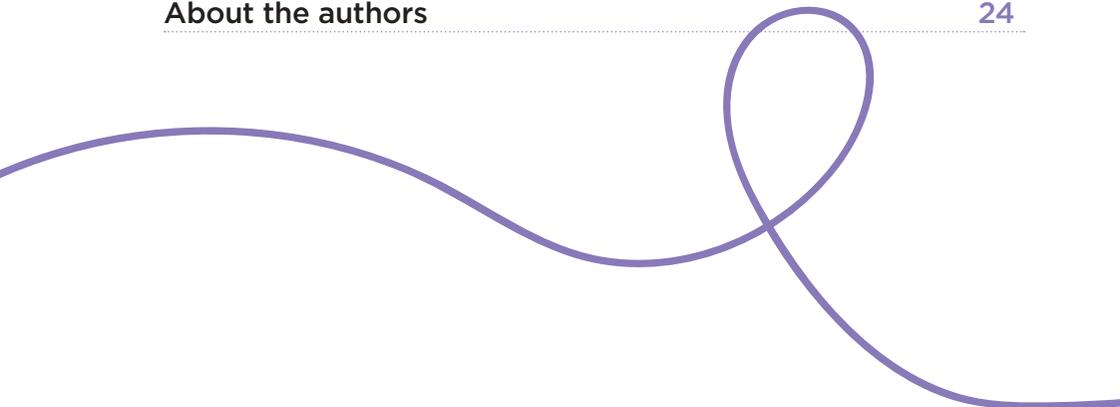
More detailed information about specific reablement programs can be found in the *service provider handbook*, which can be freely downloaded from hammondcare.com.au/reablement.



A full account of the research findings and original references can be found in the *technical guide*, which can be freely downloaded from hammondcare.com.au/reablement.

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What is dementia?

Dementia is a neurological condition (a set of medical signs and symptoms) that can be caused by a number of underlying diseases, including Alzheimer's disease. Categorised in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as a 'Neurocognitive Disorder', dementia can affect a person's memory, thinking, sensory perception, behaviour and their ability to communicate. It can also affect a person's ability to carry out everyday activities.

Although dementia can affect younger people, the majority of people living with dementia are over 65 years old. While anyone with dementia may also have other health conditions, these are more common in people over 65 years of age, and include such things as heart disease and poor eyesight. Loss of muscle strength, decreased balance and reduced physical endurance are also more common as people age.

Conditions associated with ageing and dementia can also interact. For example, we know that people with dementia are more likely to fall than people of the same age without dementia.

Despite the losses that may be associated with dementia, there is good evidence from research studies that it might be possible to delay mental and physical decline, and day-to-day functioning may be maintained or even improved, with the right support.

What is reablement?

'Reablement' refers to maintaining or improving a person's function and may ultimately lead to improved quality of life. The goals of reablement are set by each individual person. A person's goal might be to engage in everyday activities, be physically mobile and/or be able to do things they love and value for as long as possible.

Reablement programs may target very specific abilities such as maintenance or improvement in balance or muscle strength, or a more general improvement in everyday living activities or communication. Reablement is more likely to be successful when a person's overall health and wellbeing is considered. For example, ensuring good nutrition, addressing any other medical conditions, and reviewing medications.

There are many other terms you may hear concerning programs that aim to maintain or improve function for people living with dementia. These include rehabilitation, restorative care or wellness programs. They all have slightly different meanings and sometimes occur in different settings. We describe the various usages of the terms below:

Rehabilitation

Rehabilitation is the process of helping people to recover from a serious incident due to an accident or illness (for example, a fall and hip fracture, or a stroke). The goals of rehabilitation are based on each individual person. Therapy may be provided by a range of health professionals, as appropriate, and will generally aim to help people regain their previous level of function. Rehabilitation is usually delivered as a hospital or community health based program and is often quite intensive.

Restorative care

Restorative care is similar to rehabilitation in that it focuses on improving abilities, however it is usually less intensive than rehabilitation and is generally delivered in the person's home (which could be a nursing home). Restorative care programs aim to restore or improve function after some type of setback. Restorative care may also aim to help avoid preventable injury, and is generally not as intensive as traditional rehabilitation programs. Restorative care programs are delivered by allied health professionals (e.g. occupational therapists, physiotherapists, exercise physiologists, speech pathologists).

Wellness

Wellness describes a program that builds on the existing strengths, capacity and goals of individuals. Persons are encouraged to undertake activities that help promote an increased level of independence in daily living, as well as addressing some of the risks involved in living safely at home. Wellness programs are less intensive than rehabilitation and restorative care, and aim to assist a person to live as well as possible with dementia. Such programs may be delivered at a community centre, at home, or in residential care, and may or may not involve specific assessment and individual goal setting with a health professional.

In this *booklet* we use the term **reablement** to describe the programs outlined.





What does a reablement program do?

Reablement programs aim to help the person undertake the widest possible range of everyday living activities as independently as possible. A reablement program is usually developed in partnership with the person living with dementia, a health care professional, and potentially the person's family members and support persons. The person with dementia is supported to decide what they hope to achieve and the reablement program is then developed to help them achieve those goals. Current research has demonstrated that the following three areas of function may be supported through a reablement program. These include:

- 1: Supporting everyday living activities**
- 2: Supporting mobility and physical function**
- 3: Supporting cognition and communication**

What is meant by the term 'cognition'?

Cognition refers to the processes of taking in information, understanding it, storing it, and then being able to use that information in everyday life. It is described in more detail on page 17.

Supporting everyday living activities

What does this mean for me?

1: Supporting everyday living activities

Everyday living activities include the things we do on a day-to-day basis. They range from basic tasks such as showering or dressing, to complex tasks such as preparing a meal and banking.

Three approaches to reablement can be used to support everyday living activities:

An occupational therapy program:

Occupational therapists provide an assessment of the person's capabilities and examine their home environment. Recommendations may simply include showing someone how to perform tasks in an easier way, or suggesting adjustments to the home environment to improve independence and reduce risks, for example providing additional lighting, sensor mats etc.

An exercise program:

Research has also shown that everyday living activities can be supported through a graded exercise program that improves physical fitness, stamina and balance.

A cognitive program:

Everyday living activities may be supported through reablement programs that target cognitive skills (e.g. memory, thinking). Research to support specific cognitive reablement programs is currently limited. Cognitive reablement programs may involve learning specific memory techniques.

These programs usually require practise in between sessions, often with the assistance of a family member or support person.

Supporting mobility and physical function

2: Supporting mobility and physical function

Mobility and physical function refers to a person's physical ability in areas such as strength, movement, balance, coordination, endurance, walking speed or range of movement of joints. Maintaining or improving mobility and physical function can help prevent falls and maintain independence.

Two reablement approaches can be used to support mobility and physical function:

A falls prevention program:

Some reablement programs are based on prevention, particularly the prevention of falls. The risk of falls increases when a person has dementia. Falls are a major cause of reduced independence and mobility, loss of confidence, and pain. These programs may include having an occupational therapist make an assessment of the home environment to reduce the risk of falls. They may recommend that furniture, rugs or power cords are moved. They may also recommend the use of assistive technologies, such as sensor lights to light the way at night, exercises to improve strength, balance and mobility, or having a doctor review medications.

An exercise program:

An exercise program can also improve or maintain mobility and physical function. Physiotherapists or exercise physiologists may design specific exercises to increase strength and endurance, flexibility and mobility, balance and coordination.

These programs usually require practise in between sessions with a family member or support person.

Supporting cognition and communication

3: Supporting cognition and communication

Cognition refers to a broad range of thinking skills. These include the ability to direct your attention to a task, short and long-term memory (including recognition of familiar people, places and things), concentration and communication. Other types of cognition include the ability to think ahead and plan, organise and solve problems.

Three reablement approaches can be used to support cognition and communication:

An exercise program:

Exercise may benefit cognition, but the evidence in support of this is limited. Exercise can include endurance exercise (the type of exercise that makes you breathe harder, such as brisk walking or cycling on a stationary cycle) or exercise that involves co-ordination of the body, such as dance-like movements.

A cognitive program:

Cognitive programs may also benefit cognition but, once again, the evidence in support of this is limited.

Cognitive programs involve strategies and activities that are used to target different areas where a person living with dementia may be experiencing difficulty, e.g. social interaction, attention, communication and memory.

Programs may include activities designed to stimulate thinking, for example discussing a work of art, or practising remembering specific items over increasingly longer periods of time.

Other techniques may include learning how to compensate for memory changes through the use of memory prompts, e.g. using a calendar or diary to remind you of events and appointments.

A communication program:

Changes to communication are often experienced early in the course of dementia. These changes may include a reduced ability to find the right word, express yourself, understand other people, or interpret facial expressions.

An allied health professional such as a speech pathologist may design a reablement program to help with communication, including helping the person or their family to understand changes in communication, and providing helpful strategies for adapting to changes in communication. For example: chatting while on a walk, creating personalised life-story books filled with photos or other personal items, or reducing other noises such as radio, television, or other conversations to help the person with dementia better focus on their own conversation.



How can I plan my reablement program?

Setting meaningful goals

Reablement programs are based on providing the person living with dementia the opportunity to decide which areas of their lives are impacted most from the effects of the condition, and then helping them to find practical ways to work around those challenges. This is done by setting individual goals that will shape the reablement program. For example, if a person wishes to maintain or improve physical mobility, specific goals should be set for the types of physical mobility desired. Goals can be very practical, reflecting what the person wishes to achieve; they can be modest, such as making a cup of tea or walking to the letter box and returning, or more complex, such as travelling via public transport or maintaining a weekly social golf game. It is useful to think about what goals may be important to you prior to your pre-program assessment with a program provider (refer to Frequently Asked Questions, page 23 – *Who provides a reablement program?*).

Pre-program assessment

Providers of reablement programs should undertake a pre-program assessment to get to know the person living with dementia and understand the areas where that person is doing well, and the areas where they want some assistance to improve their function in everyday activities. This is sometimes known as a 'baseline' assessment. This helps the provider to design a program of reablement in partnership with the person living with dementia, which is unique to the person based on what they can do and what they would like to do. In other words, you will discuss with the provider the goals that you may have identified earlier.

Before starting a reablement program, the program provider may recommend that you receive medical clearance from your doctor, especially if the program involves physical exercise.

Choose a group or individual program

While a reablement program will be specifically designed for the person living with dementia, the program might be a one-to-one program or it may also include group activities. When the program takes place within the home, the program provider may wish to visit beforehand to make an assessment of the person's living environment to make sure that it is safe and appropriate for the planned activities.

Alternatively, programs can be conducted in group settings depending on the person's preference. These programs could be exercise-based programs or cognitive-based programs and may take place at community venues (e.g. a gym), public venues (e.g. a park) or at the program provider's premises.



How to make the most of your reablement program

An enabling environment

Reablement programs work best with some thought and pre-planning. This may mean that the environment needs to be uncluttered and free from outside distractions such as other people, children, pets, noise or activity. This will help the person with dementia get the most out of the program. There should also be sufficient lighting and use of colour contrast for the person to see and 'read' the environment. For example, seating colour should be different from the floor colour to allow the person to distinguish where the seat is. Good signage should be familiar, clear and visible to help the person navigate about the environment, especially to find toilets. Ensuring more enabling community environments may also be an important consideration. For example, choosing a smaller shopping centre early in the day may help someone to maintain independence in shopping.

The length of program sessions should be considered. If too long, it may be difficult for the person to stay focussed and the activity will be of less benefit. The time of day the program is conducted also needs to be considered because the person with dementia may be too tired to fully participate in the latter part of the day. Try to work out the time that the person living with dementia is at their best.

Program duration

Each reablement program should be planned and undertaken for a set length of time, for example two sessions a week for eight weeks. This is to ensure the program is long enough to achieve an effect, remains affordable, and also provides an opportunity to review progress and make changes to the program as needed. Additionally, it is easier to commit to a program when you know in advance how long it runs for.

What else does a reablement program involve?

Some reablement programs focus on a single activity, such as improving physical fitness. Other reablement programs combine activities such as physical exercise with cognitive exercises (such as word games or reminiscence). While the format of reablement programs may vary, the program is always focused on helping the person living with dementia achieving what they set out to achieve.

Reablement programs should be enjoyable. Many programs will include pleasant activities such as listening to music, or sing-a-longs to accompany exercise. They may also include family or support persons to help you make the most of the program.

Many reablement programs will require the participant to practise between sessions, and this may involve family members or support workers providing assistance. The amount of practise suggested by program providers will be an important factor when deciding on a program, as it is vital that both the person with dementia and their supporting persons can commit fully to the program to gain maximum benefit.

Finally, it is important to understand that all programs involve some element of risk (for example, a risk of falls from a program involving physical activity). Program providers will have thoroughly considered any such risks and developed a plan to minimise them. However, it is important that if you have any concerns, these should be raised with the provider. The pre-program assessment is an ideal opportunity for you to discuss individual concerns. This will also help you to choose the right program.

Frequently asked questions

Who provides a reablement program?

Reablement programs are designed by health professionals, but may also be delivered by support persons, family members or others who have been trained and supervised by the program provider.

How can I access a reablement program?

A program may be accessed via self-referral through My Aged Care or the National Disability Insurance Scheme (NDIS), a referral from a GP (e.g. GP management plan for allied health services), or allied health professionals could be contacted directly if paying privately. Programs may also be accessed via community or aged care providers. For additional advice, discuss this with your GP or community case manager.

How much will a reablement program cost?

There are a range of options for accessing reablement programs. The cost of the program will depend on the program you choose, whether you do it at home, in a community setting or residential care facility, and whether the program is set in a group or individual setting. A reablement program may be part of a government funded program. For people over 65 years of age, this could include a Commonwealth Home Support Program, Short Term Restorative Care, or a home care package. For people younger than 65, funding may be accessed via the National Disability Insurance Scheme. Private health insurance may also contribute to the cost. Additional costs may arise if aids or assistive technology are required or if alterations to the home environment are required. This can be discussed with the provider before commencement of the program.

References and further information

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Dementia Australia: <https://www.dementia.org.au/information>

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Notes



**‘...this booklet... makes me hopeful
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Theresa Flavin

*Person living with dementia and HammondCare
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