Community Support Essentials

My home, my life

Practical ideas for people with dementia and carers

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Thank you: The Dementia Centre and HammondCare Media are committed to providing excellence in dementia care. Older and younger people living with dementia deserve services that are designed and delivered based on evidence and practice knowledge of what works. This is achieved through providing research, training and education, publications and information, consultancy and conferences. Thank you to everyone who supported the publication of *My home, my life: Practical ideas for people with dementia and carers.*

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Foreword

Supporting the person living with dementia involves a partnership—a bringing together of the voices of people with dementia and carers, together with the best learning from research and practice experience.

That is what I believe is helpful in *My home, my life: Practical ideas for people with dementia and carers.* It presents many insightful tips and strategies that support the person who has dementia and their carer to live more independently at home and away from home—active in their community.

As well, better understanding the impacts of dementia may help both the person with dementia and the people supporting them. Learning how to communicate with more than words will be useful for the carer. And it will also help to understand that what appears to be a behaviour of the person with dementia is most often a form of communication—to be understood and interpreted, not dismissed or worse still, treated incorrectly with drugs or disdain.

Thinking about design features at home may offer enhancements that further enable the independence of the person with dementia, without losing familiarity which is so important.

Considering how best to approach a range of common activities outside the home promotes the value of people with dementia continuing to engage with the people and interests that are important to them.

No one is pretending there are not challenges for people with dementia living at home. But neither should we lose sight of the fact that the person with dementia can be an active and engaged citizen with quality of life–full of rich experiences, tears and laughter and, of course, love and respect.

We hope you enjoy the book and look forward to reading your tips, suggestions and stories too through myhomemylifebook.com on the Dementia Centre website.

~ Agnes and Donna Houston

Part 1
Me, dementia and growing older

01 Dementia and its symptoms

What we will learn

- What dementia is
- Symptoms and tips for managing
- Stages of dementia
- The impacts of ageing
- When behaviour changes

Dementia is a term used to describe a range of progressive disorders that affect the brain. There are younger people living with dementia, but it is more commonly a condition of older age, accompanied by age-related issues which we address in Chapter 2.

Our brain controls everything we do, with messages travelling to and from the body so if the brain is being affected by dementia, our daily lives will be affected too.

Different parts of the brain are responsible for different functions e.g. frontal lobe—planning and behaviour; temporal lobe—memory; limbic system—sleep, hunger.[4] The varying forms of dementia impact the brain differently which means the experience of dementia is highly individual but with some similar themes.

Forms of dementia

The most common form of dementia is Alzheimer's disease and it is usually characterised by a gradual but persistent decline in cognitive functioning. Vascular dementia is the next most common and usually involves a stepped cognitive decline due to a series of vascular events that affect blood circulation to the brain.

Lewy body disease is another form of dementia caused by the death of nerve cells in the brain. Symptoms can be characterised by fluctuations in mental state such as periods of extreme confusion and hallucinations. Falls are also common. Frontotemporal dementia (formerly known as Pick's disease), Huntington's disease, alcohol-related brain damage, HIV and AIDs-related dementia are some of the other forms of the condition. There are many other diseases that can cause dementia.

While the experience of dementia is different for everyone, and the different forms of dementia also vary in impact, it is almost always a progressive condition, with increased symptoms over time.

The human impact of dementia

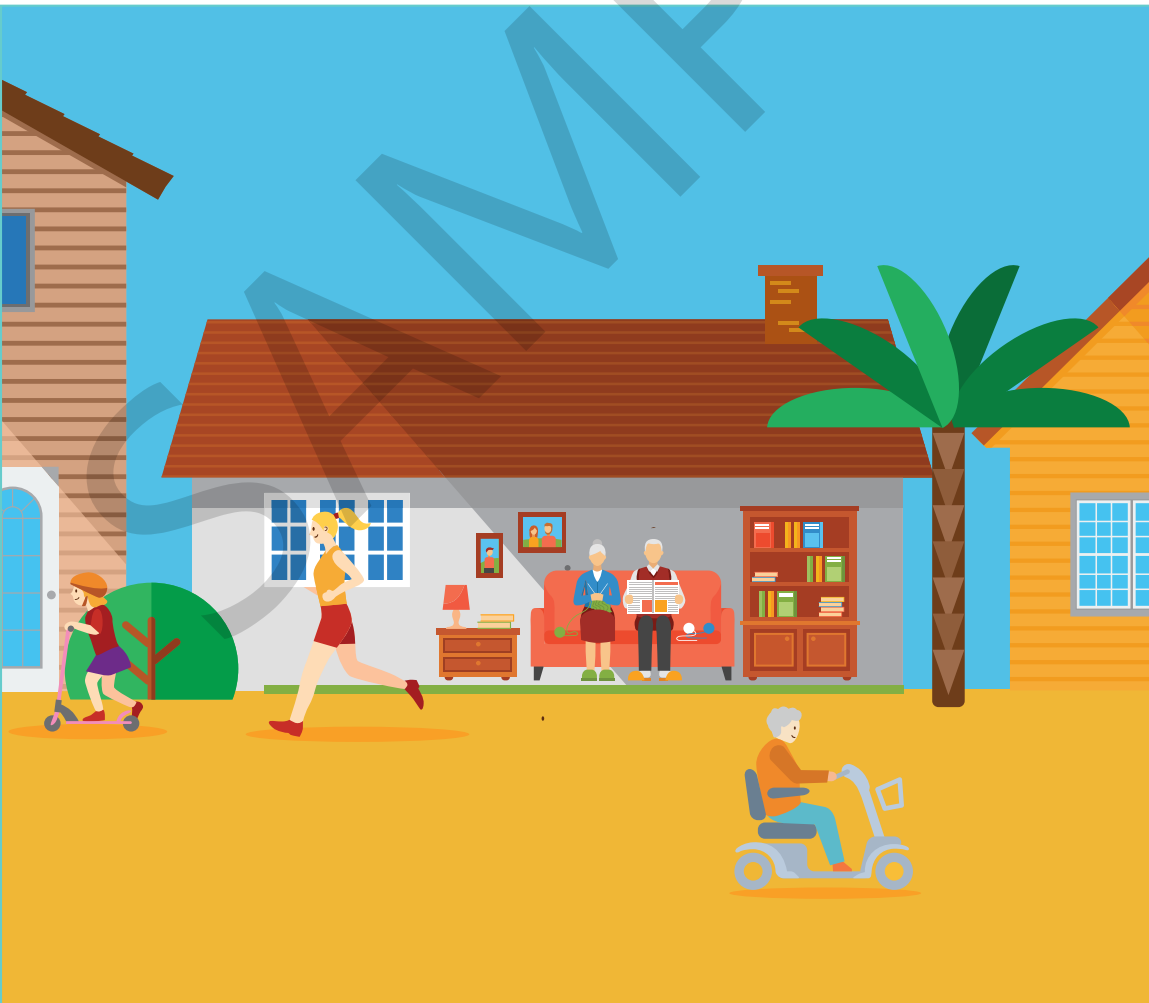
When we consider the range of symptoms that people living with dementia may experience, it is clear why a dementia-inclusive approach to design and lifestyle can help support improved quality of life at home and in the community.

Below we provide some additional detail about the more common impacts of dementia along with one or two simple tips for the person with dementia and carer. These are addressed in more detail later in the book when we look at 'Enjoying life at home' (Part 2) and 'Being active beyond the home' (Part 3).

Problems with memory

Impaired memory is very common and can impact many aspects of life from remembering a name, knowing where you are or what season of life you are in. People with dementia are more likely to retain and rely on their long-term memory, while losing their short-term memory more quickly. For example, a carer may find the person with dementia believes their dead husband is still alive (or has only just died), that there son is their husband, or that they generally approach life as if they are living 30 or 40 years in the past.

Part 2
Enjoying life at home



05 Living at home with dementia

What we will learn

- How to make the most of home
- Some of the main challenges and what to do
- Ideas for being calm and relaxed

The vast majority of people with dementia say they prefer to live at home. In Australia up to 70 per cent[19] of people with dementia live in their own homes while in the United Kingdom the figure is about 61 per cent[20].

That's why it's vital to consider how to make living at home as successful as possible for people with dementia and their carers.

Familiar is good, some change can help

Familiarity is enabling for the person living with dementia whereas an unfamiliar environment may cause increased stress and confusion. Living at home usually means being surrounded by familiar rooms, furniture, belongings, gardens, neighbourhood, people and accompanying sights and sounds. This stabilising familiarity makes functioning easier for the person with dementia than would be the case where everything is new—and at a time when learning new things is very difficult.

'I don't have to worry about being frightened'

Evelyn lives with mild dementia in her Cronulla home in the south-east of Sydney (Australia). Throughout the house are memories of her life. A beautiful photo collage that Evelyn made herself takes pride of place near the front door. Seeing all this history on display, it comes as no surprise that Evelyn wants to stay at home as long as

she can. 'I'm by myself now but I'm quite comfortable. I don't have to worry about being frightened or anything like that,' Evelyn says. 'There's something about a place like this. I feel very safe here.'

While familiarity is key, most people's homes weren't designed with dementia or ageing in mind. So while retaining familiarity wherever possible, there are a range of positive changes that can be made to enhance the home environment for a person with dementia. Some changes may help support the person physically while others may be aimed at assisting the person to understand their environment and overcome specific challenges. We'll address many of the design-related changes at home that can benefit a person with dementia in Chapters 8, 9 and 10.

Challenges of daily activities

In the meantime, some of the rhythms, routines and occurrences that are part of living at home can also be challenging over time. For the carer, it may take some adjustment to realise that daily activities that they previously took for granted are now sometimes frustratingly difficult for the person for whom they care.

Some of these challenges may be:

- getting up and going in the morning
- night-time and sleeping well
- receiving visitors
- leaving the home for planned outings
- mealtimes and eating
- making sense of home with memory and sensory changes.

The good news is that there are approaches and strategies that can be used to address these challenges, remembering as previously mentioned, that these strategies may need to change over time.

06 A good night's sleep

What we will learn

- Why sleep can be difficult
- Encouraging good sleep
- What 'sundowning' really is

A good night's sleep is a key part of having a healthy body, mind and emotions and yet many people with dementia will become light sleepers and find a good night's sleep harder to achieve. Add to this, common age-related struggles with sleeping through the night[26], and night-time and sleeplessness can be taxing issues for the person with dementia and those supporting them.

Why sleeplessness?

People with dementia may struggle to respond to night-time cues such as darkness, quietness or wearing pyjamas. Circadian rhythms (body clock) might also be disturbed by the cognitive impairment caused by dementia[27] and it is not uncommon for a person with dementia to switch day and night. The person may wake up in the middle of the night hungry and ready for some activity, which can be very challenging for an exhausted carer.

Often medications will be suggested for sleep disturbances and while they have their place, a better understanding of what may cause sleeplessness and learning some non-drug interventions should be considered first.[28]

Some age and dementia-related factors causing sleep disturbance include:

- pain—both acute (temporary) or chronic (long term)—with acute causes including toothache, earache, or pulled muscles; and chronic pain including conditions such as arthritis
- reflux and other digestive issues

- depression and anxiety
- needing to go to the toilet
- side effects of medication—e.g. sedatives can cause sleepiness during the day but make it harder to sleep at night, while some medications that need to be taken at night act as stimulants
- sleep apnoea
- not enough exposure to sun and light to synchronise the body's circadian rhythm
- lack of exercise (i.e. missing out on natural body tiredness)[29]
- daytime sleepiness
- restless legs syndrome—the sensation of something crawling on or tingling in your legs. The disorder causes the person to feel constant urges to move their legs.[30]

Getting ready for bed

George uses lighting and music to help Joan get ready for sleep. He closes up the house and pulls the curtains in the early evening, and then dims all the lights. George and Joan listen to soft, soothing music and look at photographs or magazines. Within an hour or two, Joan is yawning and ready to go to bed and sleep.

Closing the curtains and reducing lighting are good cues for going to sleep. Light coloured curtains are less stark, and be careful that reduced lighting doesn't create confusion.

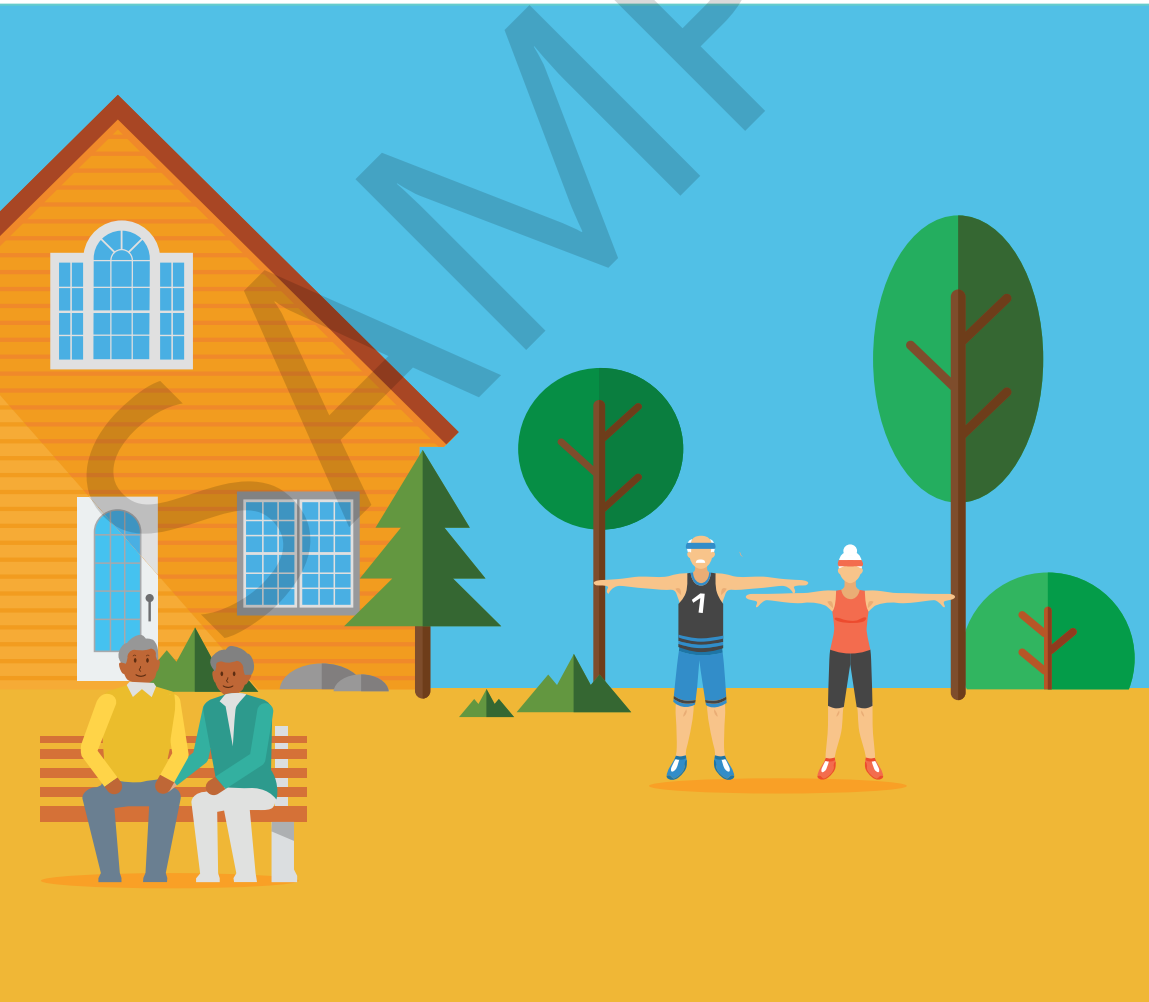
Here are some tips to encourage a good night's sleep for the person with dementia:

- Make the room as dark as possible at night. If the person you are caring for does not like being in total darkness, then consider a night-light.
- Introduce more light in the morning to activate the 'awake' hormones.[31]
- Put on pyjamas (carer too) as the time for sleep approaches. Some aged care homes have night-time staff wearing dressing gowns—another cue to show the person it is time for sleep.
- Try and exercise or have activities planned during the day so by the time evening comes, everyone's tired and ready for bed.
- Have night-time routines as mentioned above.
- Where necessary, provide pain medication before sleeping.
- Have some night-time snacks and drinks on standby if the person with dementia is waking up hungry and thirsty. This will minimise getting up and walking around which makes it harder to continue sleeping.
- Enlist the help of your GP in addressing any medical issues listed above, such as sleep apnoea and pain.

You will find some helpful bed and bedroom design tips to support good sleeping in Chapter 8.

Caring tip: To nap or not to nap? With all these possible challenges to getting a good night sleep, it's not surprising that people with dementia (and carers!) might be quite keen on a daytime nap. Avoiding a daytime nap is the advice often given as a way of increasing the person's ability to sleep through the night. However, if the person is tired, don't stop them from napping (and have one yourself when you can). We all deserve the right to nap!

Part 3
Being active beyond the home



11 The great outdoors

What we will learn

- Tips for well-designed outdoor spaces
- Barriers and solutions to going outside

It's time to turn our attention to life beyond the house. People with dementia want to remain active citizens in their communities and we know this is important to their wellbeing. This is reflected in developments such as the recent guidelines for dementia-inclusive indoor and outdoor public spaces, written with input and assessment from people living with dementia.[49]

First, let's take a closer look at life beyond the home that may often begin right outside the front or back door—outdoor spaces.

The room outside

Being outside is a vital part of life for a person with dementia, as it is for carers and any human being. The outdoors offers fresh air, sunshine, a place to clear the head and the emotions, to exercise, have peaceful reflection and to enjoy a range of pastimes and meaningful activities.

Key guidelines for dementia-enabling outdoor spaces around your home, such as your garden or yard, include:

- views to the outdoor space from inside
- easy (unlocked and visible) access to a secure outdoor space or garden
- flat, plain paths that are wide enough for wheelchairs, walkers or for two people and, preferably,
- contrasting edges on paths to help with finding the way
- familiar plants that are not sharp, prickly or poisonous
- ideally some plants that involve the senses such as herbs or flowers with pleasant perfume
- clear sight lines (remove low hanging branches, busy hedges and shrubs) so people can see clearly across the garden
- destinations along the path such as a seat for resting, or gazebo or pergola, so going for a walk doesn't seem too daunting.

These are just a few key points and there are many more in *The room outside*—details in 'Further reading' at the end of the chapter.

Meaningful engagement with familiar tasks in a safe outdoor space is ideal.

12 Leaving the house

What we will learn

- Checklist for a positive shopping trip
- Preparing for events
- Enjoying a restaurant meal

Going shopping

Heading to the shops is a very familiar activity for most people and if it remains enjoyable, it should be continued as long as possible for the person with dementia. For some people it will be possible to do this alone, particularly if close to a local shopping centre where they are well known and feel comfortable and safe. For other people, it will be an outing with a carer or support person.

Some things that will support shopping outings for the person with dementia include:

- having a clear shopping and task list—if going to a local grocer, they may be happy to keep a copy as well
- assistive technology sometimes known as safer walking technology which locates or tracks a person with dementia if shopping on their own and there is a risk of getting lost
- a specially-adapted mobile phone which allows the person with dementia to call the carer by simply pushing a button with their photo on it
- doing the shopping together and making it a social outing by stopping for lunch or cup of tea or coffee.

While often a positive experience, the hustle and bustle of shopping can also become tiring for the carer and confusing or stressful for the person with dementia. This might be time to see the shopping outing as an opportunity for some 'me time'—for both the person with dementia and carer. The Dogs4Dementia program has some useful learning around this, including that if you have a dog, they may be able to sit in a café with the person who has dementia, offering reassurance for them as they enjoy a coffee or cup of tea, allowing time for the carer to shop on their own.[50]

Dogs4Dementia has shown how an assistance dog can help anchor a person comfortably and independently in a cafe while a carer is involved in other tasks.